

Prepared for Erik's site on January 24, 2019.

## Journal

### A prologue

*April 19, 2018*

I decided to open this CaringBridge website to make it easier for people to get updates on my health status, but I still very much enjoy personal emails and letters rather than having all communications take the form of journal postings + comment threads. So don't hesitate to write to me directly at [cowright@wisc.edu](mailto:cowright@wisc.edu).

### The illness and treatment

*April 19, 2018*

I have sent many of you the following account of what's going on:

On Friday, April 6, I was diagnosed with acute myeloid leukemia. This was completely out of the blue – I had no symptoms at all. The suspicion was raised as a result of a pretty routine blood test and then confirmed by a bone marrow biopsy. Given my age and the details of the mutations involved, this is not the kind of leukemia that can be kept at bay by periodic cycles of chemo and remission. The only real approach is to try for a complete cure through intensive chemotherapy followed by a stem cell transplant which basically gives me an entirely new immune system. The whole process is fraught with potential problems ranging from glitches to set backs to catastrophes, but there is a non-remote possibility that at the end of the process I'll be fully back to normal. That's my plan!

We decided to have the treatments at the Froedtert Hospital of the Medical College of Wisconsin in Milwaukee rather than in Madison. I activated my doctorly networks as soon as I had the news – my brother-in-law at the University of Florida medical school, and two doctors in Madison. They each talked to the hematology oncologist they knew with whom they had the most confidence. And all three said that the Medical College of Wisconsin was the place to go for stem cell transplants. I managed to get an appointment for consultations on Tuesday, April 10, with the lead doctors in both the hematology oncology team and the transplant team, and felt

extremely good about them as people as well as their approach to the whole endeavor. We could have still done the first phase of the process in Madison, but it seemed better to have everything in one place.

The steps in the process, as best as I can tell, are:

1. A month of chemo, which began April 11, to produce a remission, defined as no longer detectable cancer. The chemo in this phase has a newly approved slow-release formulation which mutes the side-effects while still being more effective. So far, no nausea and no hair loss. If I get a full remission, then I move on to step 2. If not, repeat step 1.
2. 4-6 weeks of recovery from the chemo. If the cancer recurs in that period, go back to step 1. If not, on to step 3.
3. To get the information requires bone marrow biopsies. As a psychologist friend of said, alluding to rat studies, "I wouldn't press a bar for it."
3. The stem cell transplant. This involves finding a match from a registry of 27 million donors worldwide. As I understand the process, there are eight specific genetic markers, so a perfect match is 8 for 8. One doesn't need a perfect match to survive, but it reduces the chances of graft/host disease. Assuming an adequate match is found, then my entire immune system gets wiped out – not just the cancer cells, but everything. This is the kind of powerful high-side effect chemo that I associate with chemotherapy. This is going for broke. If the transplant fails, then that's it. This is like getting a heart transplant: once the old heart is gone, the new one is what you have. With a good match, then the success rate is pretty high. All of this involves another month in the hospital.
4. Following the transplant hospitalization, we will have to live in Milwaukee fairly close to the hospital for 45 days because we will have frequent outpatient appointments, and there is a significant chance of infections requiring rehospitalization during this period. The big sources of catastrophe are infections and graft-host disease. More bone marrow biopsies. This, more or less, takes us to the end of the summer.
5. If I make it through 4, then we can return to Madison, with lab work being done in Madison, and periodic trip to Milwaukee for clinic visits for six months or so.
6. By sometime next spring, back in the saddle!

I am now in the midst of step 1 of the treatment. As the lemming said in freefall half way down the cliff, "so far so good." When I wrote this to one of my students, he replied immediately: fortunately there was a trampoline at the bottom of the cliff. I'm feeling hopeful, and even optimistic, but of course there are so many ways this can be derailed that I also try to be cheerfully realistic. What I absolutely will try my best NOT to do, is let the prospect of dying in the next few months contaminate the time while I am alive. We all die. That's not news. And the one thing I know for sure that while I am alive I'm not dead. So why spoil it.

I like to think of this as an expedition into an unknown wilderness with perils rather than a catastrophe from which to be rescued. I still have no plans to retire when I get through this adventure and hope to be back in action in 2019.

## My "silver-lining" list

*April 19, 2018*

I am going to keep a running list of all of the positive things about having acute myeloid leukemia. When grad students from California come to Wisconsin and seem worried about the winters I tell them, "You need to find some reason to regret the end of winter." For me it is cross-country skiing. So, here are some items already on my list:

**1. I ate my first bowl of ice cream in 25 years.** In 1993 I switched to a strict low fat diet for cardio-vascular reasons. At that time the recommendation was just "low fat." Since then there has been a much more nuanced set of recommendations about different kinds of fats, and refined carbohydrates are now seen as especially bad for cardio health. But one constant through the 25 years is that saturated fat is bad for you, so no ice cream for a quarter of a century. The doctors and nutritionist here tell me that I need lots of calories in this battle, and that since my appetite is likely to decline, I should just drop the restrictions. Marcia got me Ben & Jerry's Cherry Garcia ice cream and I ate an entire bowl.

**2. Marcia agreed to watch *Games of Thrones*.** I enjoyed listening to the Game of Thrones audiobooks (while exercising) and had seen some of the episodes in the HBO series, but Marcia doesn't like movies with a lot of violence, so I could never convince her to watch it with me. She felt that "under the circumstances" she would give it a try. She still doesn't watch the many violent bits, but she is enjoying the characters, the saga, and the strange mélange of fantasy and medieval realism.

**3. I get a month vacation just with Marcia in an exotic location with beautiful views of Milwaukee from the 8th floor of our "home away from home."**

**4. For the first time in 42 years as a professor, my must-to-do-with-a-deadline list is empty.** When I initially got the diagnosis I knew that I would have to cancel a range of plans, especially an interesting trip to

give lectures in Italy, Germany and Norway in late May and early June. Once I got here I was told I should basically cancel everything until the end of 2018, and possibly longer. I began by informing anyone whose own plans would be directly affected by my situation, and then cancelled everything. This involved finding other people to take over various responsibilities for some conferences I had organized, arranging for my teaching to be covered one way or another for the rest of the semester, telling graduate students that I wouldn't be able to write comments on dissertation drafts, taking a leave of absence of the Politics & Society editorial board, etc. The result is an empty list of things with deadlines. I still hope to do some writing on the book I am finishing, and perhaps clearing my desk will make this even easier.

I will add more things to this list as time goes by.

## First skirmish

*April 21, 2018*

It is hard not to have a military metaphor for treating cancer. Battling cancer. Putting up a heroic struggle. Chemotherapy is chemical warfare. My doctors are a war cabinet planning their attack. The nurses tend the wounded. And the war has a narrative structure, with skirmishes and battles, strategic retreats, rallying the troops, endlessly spying on the enemy.

Two nights ago was the first serious skirmish: my temperature spiked modestly and I went through six or seven hours of chills and night sweats (I soaked six hospital gowns in the course of the evening), feeling really awful. Up until that point, I never felt sick. I could gleefully say in emails that the diagnosis was out of the blue -- no symptoms. I was immediately put on various IV-drip prophylactic antibiotics and heightened visits from staff. The fever broke around midnight and I immediately felt much better. The rest of the night was shaky, but not terrible. And during the course of the day I felt continuously better.

The whole episode fits the military metaphor. August, 1914. World War I begins. Cheering in the streets. Young men volunteer in droves in Britain. We'll be back by Christmas. They land in Flanders, march off to Flanders a couple of weeks later. All very Jolly. I was diagnosed April 6, arrive here April 11 symptom-free. I didn't cheer the war, mind you, but there was no real dread. When asked how things were going I would reply, "If I didn't have a dire illness, I would code all of this in the 'interesting' column." The illusion disappeared when I reached the front. All hell breaks loose. Confusion, uncertainty as a lived reality rather than intellectual perspective. Is this what its like? Is this the "New Normal". But then the bombardment suddenly stops. Things calm down. Now a full day later it is like being on leave from the front, hanging out in a pub, comfortable, at ease.

So, what happened was not a "New Normal", but an episode. This is reassuring, of course -- it is easier to tolerate pain knowing it will end. Torturers know this, is why they try to avoid killing someone under torture and promise and end to torture if the target cooperates. I know that there will be much worse episodes in the war

ahead and some will be extended for days, maybe longer. But there will also be periods of leave from the front.

## An old sociology professor meets a young dermatologist

*April 22, 2018*

**A background event:** I had a PICC line put in so that fluids in IV bags could go directly to a catheter that threaded to a vein that emptied directly into my heart. The procedure involves real-time x-ray images to guide the catheter. Later, I was asked by my hematologist, "Did you ever have TB? The doctors are concerned because of the images during the PICC line insertion." I knew what was at issue. When I was about 8 years old I had histoplasmosis. That left some benign scarring on my lungs. Doctors freak out whenever I have a chest x-ray. That seemed to calm things down. But a few days later....

**The scene:** Saturday morning (April 20) my lead hematologist, Dr. Michaelis, noticed some pink spots on my forehead: "Are those new?" Marcia had commented to me about them before: "Yes, they started a few days ago, right after the chemo." The doctor approached me and asked, "Are they tender?" "I don't know. Nobody's poked them." So she poked them. The largest was tender. She decided to ask the dermatology team to come and look at them. One possibility, I was told that the histoplasmosis had been reactivated by the collapse of my immune system. After 63 years? Unlikely, but histo is a fungal disease, and fungi can be dormant for a very long time. I want the dermatology team to look at this.

### **The event:**

So in the afternoon, a dermatology resident came to my room. She examined me head to toe and found a number of other such spots. She returned later with the head of the dermatology team to do a biopsy of the largest of these spots. There are many possibilities, many of no consequence, some that should be treated. Histoplasmosis is one possibility, but they will test for all sorts of things. The biopsy is to be taken from the right side of my neck, near my shoulder. I am lying on the bed. The procedure is pretty simple: a numbing shot, then a couple of thin scalpel samples, then stitch it all up to minimize the scar. She asks me what I do. I tell her I'm a sociology professor. What is your research on? I then launch into an explanation of the idea of real utopias, and that leads to a discussion of the ward at Froedtert Hospital which is my current home and why I think it has some real utopian qualities. I'm sort of giving a lecture. I emphasize one very specific aspect of what seems to be the culture of this unit: the doctors really listen to the patients. I'm speaking of course only from my observations of how I am treated: some of the doctors hang out in my room when they do their daily visit; they always listen attentively; they never seem impatient, wanting to get on with things. I go on in professorial mode: I know that efficiency matters, but here at least it does not seem to be the highest priority. The quality of caregiving, of caring, is what strikes me. The young dermatologist fellow continues to stitch up the wound, listening attentively. The lecture continues. Sometimes these issues are referred to "bedside manners", but that makes it seem more like being polite. This is about creating human connections that matter, and to really matter

they need to matter to both parties. It is hard to fake it; to pretend it matters when it doesn't.

I then paused and saw the scene as a whole in my mind's eye: me, lying on the bed with my head at the foot of the bed, chattering away about ideas, values, social analysis; and a young doctor, focusing intently on the lower right side of my neck, doing her part to heal me. I said, emotions welling up suddenly making it hard to get the words out, "I guess I'm being a professor giving a lecture." She put her hand on my chest and said some comforting words. But of course my half-sobs were not coming from despair or sadness, but from the emotional intensity of this time where my feelings of identity and connection figure so powerfully in my everyday being, not just as a background context of being. And seeing, experiencing, my identity as a professor wend its way into this particular moment in this particular way, filled me with feeling.

## Medical Update

*April 23, 2018*

I hadn't planned on using this website to give regular updates of the clinical Medical Condition report variety, but I think it is probably worth doing very short versions of that from time to time. I will call these entries simply: Medical Update. So here is Medical Update #1:

I am feeling very well with no symptoms other than fatigue. All the relevant numbers are moving in the right direction according to script. The chemo was confined to days 1,3 and 5. This is day 13. The bone marrow biopsy is schedule for day 20 (April 30) which will give us the critical information about remission during this phase of the treatment.

## Some thoughts on why I am writing this journal

*April 23, 2018*

The simplest and most obvious reason I am writing this is a kind of efficiency: Many people want to know how things are going and it is easier to have regular postings easily accessible to anyone then to send this information to people one at a time. I've decided to have a specific posting called Medical Update to make this aspect of the journal clear.

But informational updates is not for me the main thing. I am having a rich and interesting experience, and needless to say, one that triggers lots of thoughts and reflections. I know that some of you will be interested in my musings, and again, the easiest way to share is to post. I would in any case be writing these kinds of musings, something I often do when I travel. I haven't in the past ever posted my travel journals, but in this instance I thought many of you would want to read about my travel to the land of acute myeloid leukemia, so

why not share?

But there is another thing in play here, which I am finding quite salient. I am finding writing about what is happening very comforting *to me*. Comforting -- maybe therapeutic. I love to write. It is a source of joy, not just because the product may be good sometimes, but because there are moments in the process in which I feel an elevated positive emotional intensity, some combination of contentment and excitement. When I am fully immersed in writing on some interesting problem I am often thinking about it in the back of my mind all the time. One way I drift off to sleep is to think about a piece on which I am working, go over the overall narrative arc, and then think about some specific expositional problem. Multitasking sleep and composition, and waking in the morning with new ways of moving forward. Writing often makes me happy -- not always, of course: there are those damn deadlines that can undermine things. But here there are no deadlines. I'll write when I can. And share the writing with you because part of the happiness I get comes from the pleasure and meaning some of this may have for the people I love.

## Comments

I find I also do multitasking sleep and composition!

—Lefeng Lin, April 24, 2018

I'm looking forward to sharing your journey, reading your musings, and standing with you as you enter battle. If there's anyone with a life force strong enough to conquer this, it's you. with much love, devah.

—Devah Pager, April 24, 2018

I've already read the first several "chapters". Your writings may comfort you, but - this is certain - they will also comfort your loved ones. Your entries are, and will be, gifts ... to your readers. Day by day. xx Janet

—Janet Gornick, April 24, 2018

Hi Eriki,

We want to visit and see you in person, but this is a great idea in the meantime! I will read!

I don't think I mentioned this to you, but I am part of a research collaborative here at the U of MN that is called Narrative/Medicine. I can tell you more if you are interested. [Here's a tidbit -- my particular project for this group is on graphic memoirs!]

Love,

MJ

—Mary Jo Maynes, April 24, 2018

Hi Rik,

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Just a brief hello thru this vehicle. Great way to keep up with you, without harassing you with calls when you least want them. Will see you sooner than later.

Love,  
Wally

—Wally Rosenthal, April 24, 2018

I personally relate to a lot of what you said. I have been keeping diaries ever since kindergarten (as soon as I learned basic writing). Whenever I flipped through those old diaries, it was as if a time machine had brought me back to the self before and the old times, which in real life, had slipped away of course. Writing should by nature be a very comforting, therapeutic experience! It's our joy to read your pieces too!

—Dorothy Wu, April 27, 2018

For those of us, far away, it's nice to hear your voice and thoughts. Selfishly, I'm really glad you're doing it. It makes the distance feel not so far.

—Shamus Khan, April 28, 2018

## Effort & will power

*April 24, 2018*

In order to provide some gentle encouragement for patients to get some exercise, the bone marrow transplant ward has organized a "marrow-thon". The ward is configured as a figure-8. Eight full laps is about a mile, so 210 laps is about the length of a proper Marathon. If you complete this during your stay here, you get a t-shirt of someone pushing an IV pole over the finish line. This, I thought, was kind of cute and endearing -- making the activity like the weekend 10K "run for the cure." I didn't need the t-shirt as a motivator since I'm good at doing what doctors tell me I should do because of the health benefits. Still, it added a little jokey fun to the task. Ten laps a day is set as the goal. When I first arrived I walked pretty briskly down the corridors. I was without an attached IV pole, but others had them and were shuffling along. This is one of the few contexts in which I see other patients. Some walking clockwise, others counterclockwise. We greet each other as we pass, but don't really engage in conversation. I also attended at PT class designed to keep us active. Only one other person was with me in the class. Why not others, I thought. The exercise would be good for them; why don't they make the effort?

That was the first week. In the second week my energy level declined steadily; I had some very tough nights; I was operating under different parameters. A few days ago, after missing one whole day of laps towards the



marrow-thon t-shirt, I went for the walk with Michael Burawoy who was visiting from Berkeley. I'm sure we were walking too fast for my current state. After half a lap I was finding it hard to talk and walk at the same time, so we slowed down; I stopped talking; but we kept on. As we approached my room I thought, should I stop? No, I said to myself, do another lap. I started shaking as we rounded the next corner and very quickly it became clear that this was not a question of willingness to exert the effort, but of some real limit. I couldn't get words out through my shivering. Michael helped me get back to the room. I fell into the bed, and was back to some sort of equilibrium within 5 minutes.

Of course I knew before all of this that one can never really tell how much "effort" a person is expending just by looking from the outside at what they do. But I also realized that I had been softly judgmental about patients who didn't seem to be putting out the effort to go to the PT class or participate in the corridor walking. Even in this context of very sick people -- right, that's me, a "very sick person" -- I was implicitly acting out a work ethic of effort-as-virtue. So stupid. Of course, when there is a shared task and some people do not seem to be pulling their weight, sharing the burden, there are grounds for judgment on grounds of unfairness and free-riding, but that is about the distribution of effort and not the sheer fact of effort. And even there observations may be misleading because the internal burden may not map well onto perceived effort.

I have always silently felt I could deal with challenging situations through effort and willpower. Something hard might take longer, but I could expend the needed effort through sheer will. I know I wouldn't have defended that view, but something like that was in my heart. Will power may matter, and exerting effort is important for accomplishing goals, but the capacity to exert effort may just be outside of one's control.

## Comments

everyone 'hits a wall' when willpower and effort are irrelevant - the energy is simply not there to draw upon. would it help to think of it as 'trying each day to muster your best effort for the day'? Energy fluctuates - what is true for one day may not be true for the next. A gentle test of the waters might be a good effort for that day - or too much. In that case - listen to your body and stop. Your body is putting forth a lot of energy in healing itself - thank you, body!  
love, beth & woody

—Beth Wright, April 24, 2018

Hi Erik, thanks for sharing your experience with us! We send you a big hug from the south, and we want to see you with that t-shirt! Abrazo.

—Rodolfo Elbert, April 25, 2018

10 times around, hands clasped behind, which way to turn? a maze to master. what -hoe and onward? XOXO's

—Colleen Rand, April 25, 2018

Hi again, Eriki,

Your writing here is so interesting and varied. There is so much insight packed into this short post - for example, do you see how your experience is changing your capacity for empathy? Wow!

Love,

MJ

—Mary Jo Maynes, April 26, 2018

## Discussing song lyrics with my mother: "Whistle a Happy Tune"

*April 25, 2018*

Every day, I try to call my mother, Beatrice Wright, who lives in an assisted living facility in Madison. She is over 100 years old, nearly blind, very frail. Before I got sick I would try to visit her every day, usually on my way home biking from the University.

We had established a very nice routine for these daily times together. I would begin by asking her, how are you feeling today, and almost always she would answer "Good enough", and I would say, "that's the right answer, you pass the test". Occasionally the reply would be with gusto, "Good enough!!" and I would say, "that sounds like good enough plus." We would laugh together.

In recent months one of the things we would do during our visits is discuss lyrics to familiar songs. Sometimes she would suggest a song; sometimes I would. My mother was a distinguished professor of rehabilitation psychology, and often I would pick a song in which I could use our conversations to invoke her professional past and, when appropriate, the ideas that animated her academic life. Once we had chosen a song, I would look it up on the Internet. Often we would discover that there were surprising lyrics after the first more familiar verse, or on some occasions fantastic alternative verses. Last week, when I called from the hospital, we studied "American 'Tis of thee" together. The original version was published in the early 1830s as a patriotic song proclaiming the glories of America the land of liberty. In the 1840s an abolitionist version appeared:

My country, 'tis of thee,  
Stronghold of slavery, of thee I sing;  
Land where my fathers died,  
Where men man's rights deride,  
From every mountainside thy deeds shall ring!

My native country, thee,  
Where all men are born free, if white's their skin;  
I love thy hills and dales,  
Thy mounts and pleasant vales;  
But hate thy negro sales, as foulest sin.

Let wailing swell the breeze,  
And ring from all the trees the black man's wrong;  
Let every tongue awake;  
Let bond and free partake;  
Let rocks their silence break, the sound prolong.

Our father's God! to thee,  
Author of Liberty, to thee we sing;  
Soon may our land be bright,  
With holy freedom's right,  
Protect us by thy might, Great God, our King.

It comes, the joyful day,  
When tyranny's proud sway, stern as the grave,  
Shall to the ground be hurl'd,  
And freedom's flag, unfurl'd,  
Shall wave throughout the world, O'er every slave.

Trump of glad jubilee!  
Echo o'er land and sea freedom for all.  
Let the glad tidings fly,  
And every tribe reply,  
"Glory to God on high," at Slavery's fall.

We had a great time with those verses, and for me the experience of the two doing this was powerful and moving: two professors mother and son, one 100 years old, the other 71, both in assisted living facilities -- one in a retirement community, the other a cancer ward in a hospital -- discussing the lyrics of a song.

Another sweet moment was in a discussion of the line from "America the Beautiful". When I read the line: "And crown thy good with brotherhood", my mother said: "Rickey. It should be 'Crown they good with siblinghood. Otherwise people will feel it only applies to men.'" That is the mother I have known since childhood: always on the lookout for ways to improve things, and especially keen on the power of language to alter perception. Professionally she championed the change in discourses of physical disability from "Disabled persons" to "a person with a disability."

A few days ago I suggested "I Whistle a Happy Tune" from the musical *The King & I*. Broadway Musicals are

an important part of the soundtrack of my childhood. My Dad loved them. He had a special LP turntable which played one side of an LP from below and then the other side from above. In the *King & I* there is a song early on in which a little boy is afraid of the people he is meeting in Siam and his mother comforts him by telling him that when she is afraid she pretends she is brave by whistling a happy tune. An early line in the song says:

The result of this deception

Is very strange to tell

For when I fool the people

I fear I fool myself as well!

Later there is a stronger claim:

Make believe you're brave

And the trick will take you far.

You may be as brave

As you make believe you are

Here you are not just fooling yourself, you actually became brave.

Later I reflected a bit about the meaning behind the lyrics as they bear on my situation. There are no "people I fear" which need fooling, but for sure there are fearful things and I want to face these fearful things "bravely". I don't think I am making believe I am brave in order to actually become brave, but there is a shadow of that sort of idea: I know that if I focus on the fearful possibilities it will undermine my sense of hopefulness. But deliberately focusing on the positive is not fooling oneself. I am also not "putting on a brave face," which is more about hiding one's inner state from others, maybe because looking brave gets public approval. I have to admit that it does make me feel good when people comment that I am confronting my illness with courage. But I don't feel I am acting this way to elicit those compliments. Mostly, I think, I have just decided that the best way for me to deal with these fearful possibilities is to acknowledge them, and put them aside since I don't want them to interfere with my fully living my life.

That is easier to do now while I still feel physically well and the dire possibilities are still in the distance.

## Comments

Love all your reflections, Erik. Today's is particularly poignant. How lucky Beatrice is, having you as her son.

—Cathy Loeb, April 25, 2018

Your inspiration is eternal, Erik! So much love -

—Masoud Movahed, April 26, 2018

Weird - no other word for it. "America the Beautiful" popped into my head yesterday, for no particular reason, and got stuck there. I used to sing it every day in class when I was in about second grade. Haven't thought of it in years. As it wormed its way around in my ear, I was thinking about how much I love the tune and some of the sentiments, but wish some of the words were different. Gotta just be a coincidence, but ... ???

—Mary Jo Maynes, April 26, 2018

## Sideshow and The Big Top

April 26, 2018

Sideshow. A lovely metaphor used by doctors. Strolling down the Midway toward the Big Top where the main event takes place. Barkers are shouting for attention, hoping to get you into their amusement. They are insistent and very annoying, demanding you to come in. The Big Top is where I want to go, but the damn Barkers -- symptoms that scream at you -- persuade you to enter. They cannot be ignored.

**Sideshow #1. *Diabetes insipidus*.** The initial symptoms that ultimately lead to the leukemia diagnosis were extreme thirst and an almost continual urge to pee. Those symptoms suddenly emerged in early

March. It took about a week for the diagnosis to be worked out. During that time I in my undergraduate lecture I either had to avoid drinking anything for a hour before and then give the lecture with a totally parched mouth, or I had to take a break half way through to pee. Anyway, after a week of tests and a referral to the UW endocrinology clinic, the diagnosis was definitive: my pituitary was not producing a hormone needed to regulate salt balance in the blood, kind of parallel to the way insulin regulates glucose balance. Regular diabetes is *diabetes mellitus*, meaning sweet diabetes because urine tastes sweet due to the high glucose concentrations. Urine with *diabetes insipidus* has a bland taste. A nasal spray, twice a day, of a medication called Desmopressin instantly solved the problem.

Fast forward a month. I'm in the hospital for acute myeloid leukemia. One morning I gave a squirt of the nasal spray and felt that I hadn't gotten a proper spray. The recommendation in such a case is to take another dose when symptoms reappear, which I did about eight hours later, and then took a dose at night. The result was that I was slightly overdosed for a period. This leads to a fall in sodium concentration below normal levels. That led to some concern by the medical team, since low sodium levels can cause significant problems. When this worked itself out, the endocrinology team suggested that perhaps it would be a good idea to switch from the nasal spray delivery system to pills, a standard alternative, since then you never have to worry about the dose level. And, they said, a hospital is a good setting in which to do this, since often it takes some trial and error to get the dosage right; there is no simple algorithm to go from the spray to pills.

So, we began the experiment. The nasal spray dose is 10 micrograms of medication. They began with a dose of 75 micrograms of the oral medication. A larger dose is needed because the medication has to be absorbed through the gut to get into your system. That had no effect whatsoever; it was just like having completely untreated insipidus. Then 100 was tried. Minimal effect. Then 150. A couple of hours of relief, then what the endocrinology doctors calls "breakthrough", meaning that the underlying condition breaks through and full symptoms reappear. Sounds more like breakdown than breakthrough. 200 micrograms still only gave a few hours of relief. This went on more or less for a day: periods of a few hours of controlled D.I. followed by having to pee every 20 minutes. The dose got close to the upper limit. The endocrine team didn't have a specific explanation for why the oral medication was proving so ineffective, but probably it had to do with something from the chemo interfering with absorption. Experimenting in the hospital for a shift to pills sounded good, but of course this didn't take into consideration exactly why I was in the hospital. So, in the end we decided to drop the experiment and stick with the nasal spray. Works fine. The Sideshow is closed.

**Sideshow #2. Little red skin spots.** A few days after the chemo cycle ended, some red spots appeared, first on my face and then on my neck and chest. Dr. Michaelis noticed them during her daily visit and asked Marcia if they were new. Marcia, ever vigilant, could confirm that they

were. The dermatology team was called into action along with the infectious disease team. Because I had had a fungal infection, histoplasmosis, as a kid and fungal infections can be very serious with a compromised immune system, the dermatology team took this very seriously. A biopsy; increased prophylactic anti-fungal medication; daily inspections. My brother-in-law, Ken Rand, a professor of infectious diseases, was in the loop on all of this and was also concerned about various dire possibilities. Perhaps a tiger escaped from the Big Top and was wondering into the dermatology tent. But now, five or six days later, fungal infections have been ruled out, the spots are fading and the path reports indicate the condition is probably folliculitis -- inflammation around hair follicles caused either directly by the chemo or by skin bacteria, but not something that is threatening. The sideshow is closed.

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The problem with the sideshows is that sometimes they turn out to be a side door to the Big Top. You never know.

## Bobbie O's German Soul Food Ribs with sauerkraut

*April 26, 2018*

Bobbie is one of the nursing assistants assigned to me for the week. She is a very jolly, friendly African-American woman in her late 40s. The other day she was taking my vitals -- blood pressure, pulse, temp -- and remarks, "I like your hair." I then told her a little vignette from 2009:

In early 2009, right after the Obama election, I was going through a TSA check point at O'Hare airport, and a big, burly, African-American TSA official looked at me, smiled, and said, "I think there is a little bit of bro' in you." I replied, "you never know, ancestries are complicated." That was such a poignant moment. It is almost inconceivable that a black man would have said something like that to white man six months earlier. But there was this brief Obama moment, right after the election, where many blacks and whites felt maybe, just maybe, there could be some real change. Not that this would immediately be a post-racial society, but that we could begin to seriously deal with race. This guy looked at me and figured with my bushy frizzy hair and general demeanor that I had voted for Obama, and he was willing to take the risk of making a joke symbolized the dissolution of barriers.

Bobbie liked the story a lot. "You know," she said, "I sometimes have white patients who ask if they can touch my hair, and I say sure. But some black people find that offensive. I don't. I think when someone asks me that that they are just curious and want to find out. And saying yet says this is fine, we're two people. Sometimes people can be too sensitive about things like this." She went on to tell me that her dream was to open a group

home that would not be for just black people or white people or Hispanic people, but just for people.

The conversation drifted to the pleasures of diversity and how much more interesting it is than living in a world with people just like oneself:

"I once took care of a German Lady and I didn't know anything about German cooking, so she had to teach me."

"So," I asked, "you had to learn a lot about sauerkraut?"

"I sure did. I make a fantastic dish with ribs marinated in sauerkraut. You just marinate it over night and throw it on the grill. The ribs just fall off the bone."

Today, I asked her for the recipe. Here it is:

- dump a can of sauerkraut over the ribs
- add green peppers and onions
- marinate in the refrigerator overnight
- cook on the grill covered in the sauerkraut, green peppers and onions

## Comments

I did not know for a long time that Black people do not like to have their hair touched. One of my graduate students told me (we were good friends) because I touched, weighed, as it were, one of her many braids. Then, of course, I did not touch any beautiful strong black hair again.

—Magali Larson, April 27, 2018

## A technology I never knew existed (slightly r-rated entry)

April 26, 2018

In the midst of the effort to figure out the proper dose of Desmopressin to control my diabetes insipidus, I



needed to get a CAT-scan as part of the diagnosis of the possibility that my skin problem was somehow linked to the histoplasmosis of my childhood. The problem was that I had to pee every fifteen minutes. To get to the CAT-scan machine, I had to be wheeled by a transporter, wait for the CAT-scan, have the procedure, and then be wheeled back. That would take way more than 15 minutes. What to do. The solution was something called a "condom catheter". Basically this consists of a heavy-duty condomish device that is connected to a catheter that empties into a bag. I say condomish, because the material in question is quite thick -- no concern here for "sensitivity"! -- and doesn't look anything like a regular condom. The nurse then fitted this over my penis, which was a bit of a challenge given that (needless to say) it was completely flaccid. Then the idea is that you just pee whenever and the pee goes into the bag. It turns out that there is a real mechanism involved: when you pee, a kind of balloon initially begins to fill up and then the condomish device starts pumping in order to get the pee to go down the catheter to the bag. I found it a bit hard to actually pee in this situation -- lying on my back with this device engulfing my penis -- but I managed and after a couple of rounds found it easier.

Only there was a problem: Each time I urinated there was a little leakage. Not much, just a little. For someone on a normal urination cycle, this would not pose a challenge for the functioning of the device, but when you pee every fifteen minutes, the leaks seem to become a kind of lubrication for the device, which lead the thing to pop-off mid-stream, so to speak. I didn't find this embarrassing at all, but it did enable to say to the nurse, "It's been nearly 70 years since I last peed in my bed".

## Comments

This is definitely a new entry into the Pee-losophy of life :)  
Hugs and XOXO's

—Colleen Rand, April 26, 2018

## Reading "The Thing Itself" by Adam Roberts in the hospital

April 26, 2018

In late March I was in Australia to visit my daughter's family and give some lectures at the University of Queensland and the University of Sydney. While in Brisbane I had lunch with some old sociology friends who had spent time in Madison in the early 1990s, Janeen Baxter and Mark Western, and their daughter Jessica, who had recently finished an MA degree in archaeology in England. Over the years Jessica has recommended various interesting science fiction and fantasy books to me, and on this trip she gave me a book by Adam Roberts called *The Thing Itself*. The book is a philosophical rumination on Kant's idea that you can never perceive reality understood as "the thing itself" since perception is inherently structured by both senses of

perception and cognitive categories through which those perceptions take place. The conceit of the book is the creation of a form of computer that partially gets around this, which is not bound by the constraints of the human mind with its perceptual coordinates of space and time. This opens up vast new ways to manipulate the spatial dimension of the universe. This, in turn radically eliminates virtually all forms of scarcity for humanity. The style of the book is very quirky, moving from one kind of expository device to another in an engaging and sometimes a bit disorienting way. Sometimes the book is an engaging thriller with a straightforward narrative structure; other times it adopts unconventional formats that seem to meander without clear purpose. I like this kind of book and just relax and see how the sense of it builds cumulatively, rather than worry if I am tracking it as I read.

Anyway, I began the book a week or so ago. By the time I was in the hospital I was about two thirds of the way through and came to a passage that powerfully resonated with my illness and hospitalization. The year is 2350. A/K refers to Applied Kant. This is one of the chapters with very unconventional format: the paragraphs are numbered and combines an account of the principles of social existence in this post-scarcity world with a specific story of one person's dilemmas in figuring out what it means to be happy. Here are a few earlier paragraphs that set the context:

5. O this = the Utopia all of human history has peered towards. Dimly spied and now made real. Life is shaped by the principle that any individual desire be permitted +enabled + curbed only by one thing. The blanket genetic reinforcement of definitional human empathy. No,

6. no not that you *can't* hurt others or you would be a robot. What you can't do is stop *caring* about others – because caring makes us human. So, so hurting others causes you far more than you might gain by doing the hurting.

7. That one tweak = enough. Otherwise humanity lives in a post/scarcity economy enabled by A/K. which = smoothing out of spatial difference, + the access to raw materials + energy from anywhere in the cosmos.

8. A/K also enables travel anywhere you like. It turns out there are very few places worth traveling, but if that is your itch, but all means scratch it.

.....

11. Whatever your itch, by all means scratch it.

12. Ah! But if your itch = harming others? O o then it *will* cost you more than the pleasure you might get in scratching. Empathy is baked hard into us all. This the thing about which there = no negotiation.

13. But it dont matter that there is no negotiation on this one thing, because – hey, Utopia!

14. The fact that you are hardwired to care about the welfare of others don't impede you because everybody else's welfare = pretty good, thank you on account of – hey! Utopia! If you are in pain, we have the means to heal you.

Then came the passages which resonated so poignantly:

15. Except the bereaved. They hurt and cant be helped

16. But that's mortality, + happens rarely. There's nothing can be done about death, except to acknowledge it, to live through the death of others + stop living at the precisely the moment of the death of each of us.

This so closely tracks the way I am thinking about these things, and to encounter the passage in a novel that also invoked Utopia at precisely this moment was deeply moving to me.

A few pages later (p.258), in a chapter with a completely different format and style, there was another riff that perfectly intersected some of my own preoccupations. In the early 1970s I wrote a manuscript, never published (but available on my website), called "Chess Perversions and other diversions" in which muck about with the rules of chess to produce different sorts of variants. In the novel there is a discussion of the idea of structure and how it affects action. A key character in the story thinks of structures as prisons. The computer that embodies A/K says:

Oh, *prison* isn't the best way of putting it. I mean: if you're a chess piece, would you regard the squares on the board, and the rules determining how you can move, *prisons*? Not if you want to play chess you wouldn't. They're just the necessary structuring frame for your game. Of course, because chess is simpler than life, you can quite easily change the rules: move our pieces any way you fancy and so on. But that doesn't make the game more interesting. It makes it *less* interesting.

Life, death, meaning, Utopia, structure & agency, and chess. What a potent concoction for me to read in a hospital bed while battling acute myeloid leukemia.

## Comments

Hmmmmm

I remember the chess thing - didn't you also make a film of the chess pieces in rebellion? Or did I just imagine that?

—*Mary Jo Maynes, April 26, 2018*

Erik, wonderful to hear how you are going and to be able to keep up with your journey. I am so glad the book was fun and I know Jessica will be keen to recommend more for you. Keep posting. Much love from all of us .  
xxxx

—*Janeen Baxter, April 27, 2018*

So glad you liked this book. When I read it many things resonated and when I read the utopia chapter I thought

of you. I also liked the structure and agency. I wonder if Adam Roberts has read Erik Wright? Sometimes it sounds like it.

—Mark Western, April 27, 2018

I feel ashamed because it is not my type of book, being too ensconced in the here and now to think about 2350, but I like the AK idea! Sometimes the most trite aphorisms are also the most "sticky," those that never leave us --perhaps never should? -- that living is the beginning of dying, so that every day is both things. Without structures, and I don't play chess, I don't think we can even SEE anything.

—Magali Larson, April 27, 2018

## Medical Update

April 27, 2018

Today is Day 17. All of the relevant numerical indicators have moved in the right directions. I'm feeling pretty well physically, just a bit tired. In this phase of the treatment, the chemo has a slow-release formulation, which keeps the chemicals in one's body for a longer period of time and has fewer side effects, but is apparently, if anything, more effective. I have not had any real chemo side effects to speak of; those will come in the chemo associated with the stem cell transplant when that occurs.

On Monday, April 30, I will have a bone marrow biopsy to see if I am in remission from active leukemia. If so, this means we can proceed with the next steps. If not, we have to repeat this round of chemo.

## Comments

Fingers crossed.

—Colleen Rand, April 27, 2018

Fingers crossed, me too. I hope the Mural Arts Program lets you know that I sponsored a Restorative Justice program in your honor, because I know you like them!

—Magali Larson, April 27, 2018

Erik, I'm thinking of you today and hoping you get good news from the biopsy!! much love, Devah

—Devah Pager, April 30, 2018

## The story of Rogue Hematopoietic Stem Cells

April 28, 2018

### A tutorial on hematopoietic stem cells.

One of the very special things about hematopoietic stem cells is that they are all poets, or at least aspiring poets. Even the least talented can be said to be a little bit poetic. Blood poets, the poetry of blood. Sing to the wondrous joys of clotting, the vigorous enthusiasm of red blood cells taking hemoglobin where it is needed, the sly stealth of white cells.

Hematopoietic stem cells are tiny little shmoos. [If you don't know what Shmoos are, you can read about them starting on page 3 in my book, *Class Counts*: [Chapter 1](#)]. Like Shmoos, their only purpose in life is to make you happy. They do this by turning themselves into things you need. For the shmoos of *Li'l Abner*, these are the necessities of life; for our hematopoietic shmoos, they are all of the types of blood cells you need to live. If you need more white cells of different sorts to do battle with nasty invaders, the stem cells differentiate into whatever type of white cells is needed. Need more platelets? No problem: the stem cells start differentiating into platelets. And like the shmoos I wrote about in *Class Counts*, they duplicate themselves -- divide and make replicates -- because they want to be sure you won't run out of them. Busy busy busy. Copy & differentiate, continuously, intensely, from morning to night, year after year. My hematopoietic stem cells have been doing this with vigor and enthusiasm for over 71 years.

Hematopoietic stem cells live and differentiate in bone marrow which is a lovely medium for keeping them happy. But they don't stay put. Many of them leave the bone marrow and wander around the body looking for vacant housing in other sites of bone marrow. HSCs don't just sit idly by observing the world; they're continually working, vigilant, productive, hardworking members of my inner universe. And there are billions upon billions of them.

### Rogue cells

Periodically, some cosmic ray from the Big Bang hits a hematopoietic shmoo while it is making a copy of itself, or perhaps some little typographical error occurs in the copying process (we all

know how hard it is to avoid typos), and the new HSC is not an exact replica of the original. Often when this happens, the duplicate just expires: it won't work properly. But sometimes the error -- which the powers that be call "mutations" -- don't kill off the newly minted HSC. Maybe this doesn't matter; nothing important changes. But sometimes it does matter, and the cell has been altered in ways that erode its shmooiness. Time goes on, another mutation occurs, and suddenly the stem cell has become an anti-schmoo, a rogue hematopoietic stem cell whose sole purpose is to make life miserable for the universe which it inhabits. They produce defective differentiated cells that refuse to do their jobs properly, or even worse, do things that actively harm the body in which they live. From aspiring poets of blood, order and health, they become demons of blood, mayhem and death. They're angry, sullen, creepy. They've lost their way.

These Rogue Anti-Schmoo Hematopoietic Stem Cells -- RASHSCs -- like to divide even when more of them are not needed. Copy copy copy. Push out the responsible ShmooHSCs; encroach on their space; take over the bone marrow. Enter the blood stream; wander around the circulatory system of the Universe and find new homes. Copy copy copy, always copy. More and more copies living in every nook and cranny of the bone marrow. Spew out ever-more defective differentiated progeny. Relentless. The shmooHSCs are confused. Sometimes they see mutant cells as aliens and attack them, just like they would a bacterium. But these rogues seem familiar. They are neighbors. Maybe not friendly neighbors, but neighbors nevertheless. The shmoos don't know what to do. They get demoralized.

Time passes. Copy and differentiate; fill all the niches; spoil the neighborhood; garbage on the lawn; broken windows, Unhappy shmoos and arrogant rogues. And then a threshold gets crossed and the Universe Shakes and Sighs.

## Comments

Who but you could make Shmoos the heroes of our blood :)

—Colleen Rand, April 29, 2018

## Scattered Musings on Life and Death

April 28, 2018

Like everyone who gets a life-threatening illness, I have been thinking about life, death, meaning. Not morbid or grim thoughts, but maybe that is in part because the outcome is still hopeful and I am feeling physically quite well. Perhaps if it should come to pass that the treatments don't work and I feel physically awful and death seems more immanent, it will be harder to discuss these topics in a cheerful matter-of-fact way. In any case, for me I feel a stream of new insights. This is a period of many mini-epiphanies.

I won't try to organize these thoughts into a sustained essay. I'll write them as they come to me. But first I think I should put on paper my basic grounding about the "meaning of life" and other things touched on by religion.

### **On being a happy atheist**

I don't believe in God, certainly not in God as a Powerful Being that intervenes in the universe with purposes. If God is just a term that taps into the wonderousness and joyfulness of conscious existence, then I certainly believe in that, but I don't see the point of calling this "God."

I'm less sure about how to relate to the idea of "spirituality." I certainly do have experience of deep connection to other people and to nature, and sometimes this feels congruent with expressions like being "at one with the universe." Empathy, kindness, love -- these are all powerful and take me beyond myself. Is that "spirituality"? I also, accept the general idea of emergent properties and the proverbial "the whole is greater than the sum of its parts"; in terms of the web of human connections in which my life is lived (which is a specific kind of "whole is greater than the sum of its parts") this also might be a way of thinking about a "transcendent reality" beyond my own existence. But this is still just transcending *my* reality rather than transcending reality as such. Is this spirituality? Perhaps what people experience as spirituality taps into to these same things.

Back to religion: To put the matter simply, I believe that humanity has created God rather than God created humanity. God is a creative product of the human imagination grappling with difficult and perhaps unanswerable questions. There is no meaning or purpose in the universe except those meanings and purposes which we create. The same goes for moral principles: something is moral not because some all powerful and wise Being as declared it to be moral, because there are good reasons to believe it to be so.

Human life is a wild, extraordinary phenomenon: elements are brewed in the center of stars and exploding supernova, spewed across the universe; they eventually clumped into a minor planet around a modest star; then after some billions of years this "star dust" became complex molecules with self-replicating capacities that we call life. More billions of years pass and these self-replicating molecules join together into more complex forms, evolve into organisms which gain awareness and then consciousness, and finally, eventually, consciousness of their consciousness. Stardust turned into conscious living matter aware of its own existence. And with that comes consciousness of mortality.

The extraordinary and wonderful thing in all this is to be alive and aware of being alive. Most matter in the universe is neither living nor conscious. That I as a conscious being will cease to exist pales in significance to the fact that I exist at all. I don't find that this robs my existence of meaning; it's what makes infusing life with meaning possible.



When I was young, I was actively hostile to religion. In High School in Kansas I debated classmates about God. I was not hostile to the kind of moral community that could be formed around religion, but I was definitely hostile to the content of belief about the supernatural. I was raised as a Unitarian and was very active in the Unitarian's youth group, LRY -- liberal religious youth. But this was a totally secular group concerned with moral issues, social justice and community, not with God.

Over time I have become less judgmental, I think, in my views of what are these days called "faith communities." My judgments are focused much more on how people behave, on the active values that bear on how they treat people and live their lives, and not the symbolic ways they ground those values and meanings. If the stories of Jesus are the way to anchor humane and just ways of life, than that's fine. When religious beliefs cross the line and make claims about how the world works -- creationism denying evolution for example -- then, of course, I am judgmental about content because I believe those claims are just plain wrong, not merely symbolic ways of expressing meaning. But when the beliefs help ground deep concerns for human flourishing in a just and humane world, then I am more than just tolerant; I feel accepting.

### **Sadness at the prospect of being dead**

I recently listened to a very interesting program in the podcast "Philosophy Bites" featuring the philosopher Shelly Kagan talking on "Death and Deprivation." One of Kagan's arguments was that if one did not believe in an afterlife, then it was irrational to "fear" death. Believers in an afterlife might have good reasons to fear death, at least if they believed in Hell. But if you believe that your existence ceases entirely, then being dead is not an experience; there is nothing unpleasant about it. The process Dying might be something to fear because of pain and suffering, but not being dead.

There is, however, another issue around the emotional state facing death: the *sadness* about one's prospective nonexistence. I've been thinking a lot about this: what is it about the possibility of my dying in the next few months that makes me feel regret, sadness. Two quite different things have struck me about this. One source of regret is about not knowing how certain stories turn out. I want to know if the Republicans get clobbered in November. Will Trump get his comeuppance? Or at a more personal level: I have two marvelous, delightful, engaging grandchildren, Safira almost three and Vernon two and half. What will they be like as teenagers? as young adults? They are already interesting people; I'm curious how their stories "turn out." This is like watching an exciting and interesting movie and leaving a half hour before it is done: it is disappointing not to see the ending. This face of anticipating being dead make life itself a narrative which I am consuming, watching as spectator. The focus is on me and my experiences of the world.

But there is another face of regret and real sadness. This is about not being in the story, not being there to help the people I love, and especially now for my grandchildren, not being there to shape the kind of persons they become. This isn't at all because of any doubts about the parenting my grandchildren will receive. But I think I have something special to offer them which will enrich their lives in meaningful ways. When I think of their lives unfolding I want to be there *for them*, not just for the pleasure they bring to my life. (When I talked to Marcia about this, she said that when she thought about this, her immediate feeling is that what she would regret if she died is not being there to *protect* them. For me, it is not being there to *influence* them). This is the face of sadness about the prospect of dying that is most connected to love. The first face of



sadness is really all about me: what experiences I won't have, the interesting stories that will be cut short; the second face of sadness is much more about my concern for others, about love. The second of these is much more painful to contemplate than the first.

### A metaphor

When talking to people about how I am feeling about my illness, I've come up with the following metaphor. Imagine you have a really crappy, miserable, boring job that you hate. And then you go on a fantastic four week vacation of hiking in the mountains, immersed in glorious nature. The weather is fine. Three weeks past and you begin to dread the prospect of going back to work, so the last week you spend moping and feeling sorry for yourself. The result: you only have a three week vacation.

## Comments

It is profound and beautiful. I wanted to give it time. Part of the sadness is also knowing how much those you love will feel bereft, will miss you. I am waiting for tomorrow's news with trepidation.

—*Magali Larson, April 29, 2018*

## more scattered musings

*April 29, 2018*

### My bike accident versus Acute Myeloid Leukemia

A year and a half ago I was hit by a car while biking to visit my mother. The car made a left turn while I was in an intersection; the driver had the sun in his eyes, and didn't see me; he hit me broadside, breaking my left leg in four places and destroying my bike. I was wearing a helmet, but still was unconscious for about five minutes and had a mild concussion. I have no memories whatsoever of the accident -- my memories stop five minutes or so before I was hit and don't resume until a couple of hours later.

With very small changes in the parameters of the accident I would have been killed. The car

that hit me was a small, low slung Toyota. When I was hit, I am told I ended up on the hood of the car. If had been a souped-up pick-up truck or SUV and the driver had been accelerating into the turn, I would have been knocked into the street and perhaps even run over by the vehicle. I certainly could have been killed. As it was, I was a bit damaged, and the recovery was arduous at times, but overall this was not such a big deal. In particular, it was immediately clear to me -- once I regained full awareness in the trauma center -- that I would survive and the only issue was how challenging the mending and rehab would be.

The acute myeloid Leukemia is a different experience. From the initial diagnosis of diabetes insipidus in early March to the diagnosis of Leukemia on April 6 was a little less than a month. And now, laid out before me, are a series of steps I will go through with different possible outcomes. Death is a distinct possibility, but not a certainty. And I know this now, at the outset. Plenty of time to contemplate the implications.

Both encounters bring home a central fact about being alive: There is an ending, it can be from one second to the next; it can be at the end of a known-in-advance set of perils during an illness; or it can in an indeterminate future. The Leukemia scenario is much better than the obliteration in an instant, not just because there are grounds for hope, but because it is an *experience*, a form of living that enhances and intensifies feelings and, perhaps, understanding. Maybe if a later stage is also one of intense physical malaise and suffering there will seem nothing positive. But for now, eis.

## Comments

Wishing you all the best, Erik. I had a good time today with your students. Thank you for inviting me to Madison. Just discovered your page and posts here today, and appreciate how you share your experience. You are truly a sociologist to the core, and an inspiration in so many ways. Your attitude towards society and life itself is something that will stick with me forever. Sending you all the positive energy I can! Hope to meet you again and discuss life, science and sociology.

—*Eli Smeplass, April 29, 2018*

Betsy and I read your musings with int

—*John Posner, April 30, 2018*

And dont forget that this experience is not exclusively individual! I think that accompanying you through it (even for those of us far away) is enhancing our understanding of life too. Abrazo!

—Rodolfo Elbert, April 30, 2018

## Another conversation with my mother

April 30, 2018

### A three-way coincidence.

1. I called my mother yesterday afternoon. I asked her how she was feeling.

"Good enough."

"I'm good enough also, so that makes two good enoughs."

This time instead of discussing a song, I just talked about details of how various people were doing and what they were up to. Mostly she would just acknowledge what I had said with a "that's nice". But then I talked about how my brother Woody was doing. Woody was diagnosed with multiple myeloma for over a decade ago. [In case you're thinking that maybe there is a family vulnerability to blood cancer, the probabilities are not that low that siblings in their 60s and 70s both get cancer. 40% of Americans get cancer in their lives and 25% die from cancer.] Two years ago he had an advanced form of immunotherapy which has completely rid him of the disease. The recovery from that treatment has been very arduous, but he is now back in the lab (he is a cell biologist at the University of Teexas Medical School) and doing real science.

"Woody's doing really well," I said. "He is back in the lab, doing real science. He is really excited about what he is doing, and that is even more important than any achievements.

There was a pause, than my mother interjected, "Well, I would say *almost* as important."

What a lovely retort.

"Mom," I said. "You have been correcting things I say for about 70 years, ever since I first began to talk. I think it's wonderful. You know, when I was younger and you would correct me on something like this, I would often find it annoying."

"Yeah, that's right."

"But now I find it wonderful. You have my permission to correct me on anything you like."

"That's good," she said.

My Mom's still there, at her core.

2. Then this morning I got a wonderful email from a former student, now very established professionally with a strong scholarly career in a top level department. She wrote the following:

"I could of course enumerate all the debts I have to you -- you trained me, and I learned many of what I consider my best scholarly virtues from you. But you also gave me something much deeper: the simple (yet profound) lesson that the joy is always in the learning and next to this the career doesn't really matter much. It's been my guiding principle for all these years. Ironically, until I learned of your illness, I hadn't even fully realized that it came from you. But of course you showed me this with your infectious love for your work and teaching, your commitment to your students and their work, and your refusal to be distracted by the trappings of professional success (even though you accrued plenty of it over a very accomplished career)."

Yesterday I said to my mother that Woody's excitement at his research was more important than any achievements that came out of it, and then today I was told that an important thing a student feels she got from me was that the joy is in the learning, not the career.

3. In today's New York Times there was a nice op-ed celebrating the 200th anniversary of Marx's birth. One passage in the op-ed really struck me: "If ever there were a convincing case to be made for the dangers of philosophy, then surely it's Marx's discovery of Hegel, whose 'grotesque craggy melody' repelled him at first but which soon had him dancing deliriously through the streets of Berlin. As Marx confessed to his father in an equally delirious letter in November 1837, 'I wanted to embrace every person standing on the street-corner.'"

The quote adds a dimension to my statement the excitement of research being more important than achievements, and the idea of the joy being in the learning rather than the career. Marx, in his letters, expresses the way the excitement in ideas can become part of encompassing love "wanting to embrace every person on the street-corner."

These days I'm feeling in a life-affirming way the nexus of excitement in ideas, creativity, kindness and connection with others, and love.

## Comments

So beautiful, Erik. And I can totally hear your voice and intonation in "You have my permission to correct me on anything you like."

Your student chose just the right word: the joy is definitely infectious.

—Cathy Loeb, April 30, 2018

Yes!

So true/you!

Last bit also reminds me of the Young Marx movie (not the play!)

A.O. Scott called it a kind of "bromance" - a good analogy - but also the fun is there, so often forgotten. AND, Mary Burns is there, as she should be.

—Mary Jo Maynes, April 30, 2018

## My Silver Lining List, continued from April 19

April 30, 2018

Over the past two weeks I have become aware of other silver linings to having a life-threatening illness:

**5. Saying out loud wonderful things.** I have received many wonderful emails and letters once word of my illness had come out. They all contain words of support, of concern, of kind thoughts. These all matter greatly. But in some of the messages, people say in detail the positive ways in which I have affected their lives. Some refer to specific incidents, moments in our relationship; others to very specific ideas or values or ways of living that I conveyed to them in one way or another. These are things one doesn't express in life-as-usual contexts. Some get said at retirement parties, and perhaps at milestone birthdays. But in everyday I life, people don't say in detail the ways in which their lives have been enhanced by someone else. I have found these communications very moving in many ways. It is gratifying, of course, that people I care about and feel good about the positive ways I have affected their lives. But there is more going on here: these affirmations also make me feel *known* for who I really am. And this makes me feel more deeply connected to these lives that have intersected mine over so many decades.

**6. Epiphanies big and small.** There is no doubt that I have gained greater clarity on allsorts of things, even over these first few weeks of my "journey", as people are fond of saying. Indeed, the journey metaphor itself is a kind of mini-epiphany. I have always found it a bit off-putting when people use the metaphor of journey to describe personal development. It has a New-Agey feel, which I have never liked much, in part because it often carries whiffs of faddishness and inauthenticity. But here it really resonates, and I appreciate the interplay between a path forward and uncertainties -- even perils -- that the metaphor contains.

More seriously, I have had what for me are meaningful new insights and understandings about important issues

that make up a life. One concerns the character of the regrets I feel in the face of death -- the regrets as a spectator of the on-going stories which I observe, and the regrets as a participant in the lives of people I love. That contrast is in sharp focus now; it wasn't before. Another concerns the centrality of love in my life and the way love infuses my life with meaning. I have thought of meaning-making as largely a cognitive activity of rational thought and analysis. Human create meaning in their lived universe rather than having meaning given to them by some supernatural force. And, of course, I still believe that. But I also see how that task is itself underwritten by love, by the connections that bind us together in caring relations, relations that generate meaning. I don't think I would have come to these realizations in the absence of my illness.

## Comments

Can't resist a comment on the 'journey metaphor' - glad you have changed your mind. Since the days when I started writing about working-class autobiographies, various forms of the journey metaphor have been of interest. Yes, there are the new age varieties (often adapted from more ancient forms). But there is also a specifically socialist variant. The book title, *Taking the Hard Road*, was based on the titles and journey metaphors of early French and German socialist autobiographies.

—*Mary Jo Maynes, April 30, 2018*

## Medical Update

*April 30, 2018*

Earlier today I had the critical bone marrow biopsy that will provide the needed information for the next phase of my treatment. That information should be available on Wednesday sometime. As for the bone marrow biopsy itself: I decided after the last one to ask my sister-in-law to prepare a guided meditation for me on pain management, which I practiced for a four days. I will describe this in a separate posting, but the contrast with my previous biopsy was striking: This one was virtually pain free. Amazing.

## Comments

that's incredible. i'm so glad it was a less painful experience. a testament to your focus, and to the work you put into harnessing those extraordinary powers of the mind. here's hoping for good news wednesday! xox

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—Devah Pager, April 30, 2018

## On love: personal, philosophical, sociological

*April 30, 2018*

I don't think the word "love" has appeared in any academic writing I have ever done. Perhaps it snuck in in some of the writings I did on the family and intimate relations and why these pose specific complexities for the analysis of gender oppression compared to class and race oppression. But love has certainly not been an important theme.

My lived experience over the past couple of weeks has brought love to the forefront of my consciousness and my efforts to make sense intellectually of what all of this means.

Love crept in explicitly to my thinking about my illness and my connection to people on April 10 when I went to my graduate seminar on Real Utopias to say good bye to the students. I hadn't planned what I was going to say, wanting the immediate setting to shape my thoughts and words. I talked about how meaningful the seminar was to me, how wonderful they were, how grateful I was that they were enthusiastic about taking responsibility as a group for seeing the seminar through to the end. And then I spoke of love as binding us together through the care we are feeling towards each other, how this has animated my academic life and my mentoring of students, but also how much love from my students sustains me. It was all very emotional. I choked up at times. There were tears.

Since then I have thought a great deal about love.

Love is closely connected to the contrast I have made between the two kinds of sadness or regrets I feel in contemplating my death -- missing what is to come in some of the wonderful, interesting stories I am observing in my life; and not being able to help and influence the people I care about as their lives unfold, especially my grandchildren. Both matter. The first is about me; the second is about a relation. It is about love, not about me being deprived of some desirable experience by dying.

The many messages and letters I have received have filled me with the love of family, friends, colleagues and former students. There is always a sense that we are all alone in our bodies, and a severe illness creates such a self-focus on one's body that this aloneness, separateness, could be intensified. And feeling alone can easily slide into loneliness. The

affirmation of my connections to so many people as connections of love blocks any lurking loneliness and softens that sense of being alone in my body.

I also think that love is connected to one of the central themes I have been working on as I try to develop a more comprehensive framework for *emancipatory social science*. When I wrote about this, I discuss four anchors of an emancipatory social science: 1. Normative foundations. 2. The diagnosis and critique of society in terms of those foundations. 3. Alternatives to the world as it is that better realize those normative ideals. 4. A theory of transformation -- how to get from here to there. In the first of these elements, I mostly focus on three clusters of values: Equality and fairness; freedom and democracy; and community and solidarity. Most of my energy has been devoted to the first two of these. Only now, as I am writing the last chapter of the book on which I am working is the third cluster coming into the foreground.

What I now see clearly is that community and solidarity as normative ideals are deeply connected to love as a reality in the lives of people. The ideal of ever-expanding and more encompassing webs of solidarity and community as part of the real utopian aspiration for a good society also means enlarging the ways love permeates social relations. The most poignant realization of this for me right now, in the present moment, is the 27 million person registry of stem cell donors, and the three people who have now been identified as "perfect matches". These three people somewhere in the world have volunteered to help save my life. Strangers I will never meet, but we are bound together by love. "The kindness of strangers" is on my mind, and kindness and love, of course, a close friends.

My thinking about love so intensively also draws me to new reflections on religion. I'm sure this is a glib characterization, but I see much organized religion as anchored in two fundamental emotions: love and fear. Putting aside the mythic stories that are woven into religions -- which are fine as stories and parables, but not as claims about how the world works -- religions tap into fears people have, especially I think, fears about mortality. Religions often increase the fear of death by visions of hell, and then use that intensified fear as the basis for discipline and social control. But another grounding of religions -- most? many? all? -- is love. Even when this is formulated in terms of "God's love", it can still be an affirmation of the love of life and the love that binds the lives of people together.

I think love and fear come together in one of the critical ways that religion helps people make sense of their lives: in the death of loved ones. Bereavement is a universal experience. Religions at their kindest and best help people grieve by envisioning being reunited with love ones.

## Comments



Erik, I read this while I am waiting to know what the doctors said about the first round's results. I know how you are thinking. Many years ago, I was on the board of social programs of a small Lutheran church in North Philly. One evening of snow --big big snow, I had taken the subway and some friends from Erie picked me up and took me to their house near the church-- I walked in the high snow toward the church. A Puerto Rican kid was shoveling and I stopped to talk to him in our language, Spanish. Pastor Patrick Hansen, who later returned to his native Minnesota, had turned the lights on. I knew he had some light dinner fare waiting for the board, and that there would be heat and light. I understood all about churches as communities and the love they signified. I never had experienced anything like it in the Catholic education that I so ardently rejected! We are waiting, with all our love lit up.

—Magali Larson, April 30, 2018

This is wonderful, Erik. Thank you for sharing. For me, radical politics have always been an expression of love. Something akin to Cornel West's dictum - "justice is what love looks like in public." I very much felt that warmth the first time we exchanged emails, and when we exchanged a hug the first time we met. I hope to continue that relationship with you over the coming years, as colleagues and friends.

—Adam Szetela, May 9, 2018

## Meditation to attenuate the pain of bone marrow extraction

April 30, 2018

My first encounter with bone marrow biopsy (BMB) was on April 4. It was quite painful, but only for a few seconds, excruciating. It was sufficiently unpleasant that it cast a shadow of dread over the next time I was to have the procedure. That was today.

I have been doing mindfulness meditation since 2011, and I figured it was worth seeing if a meditation practice focused on pain alleviation might help. After all, I hope to have many BMBs in the future, since that can only happen if everything goes well with my treatments. My Dad was a professor of Psychiatry who specialized in hypnosis, and he certainly used hypnosis as a way of helping people deal with pain. Meditation, I assume, taps into some of the same neurological processes as hypnosis. As part of my own meditation practice (as we meditators say), I do what Marcia calls "multitasking meditation" in which I meditate while exercising vigorously on an elliptical trainer. Often when I do this sweat trickles down my forehead into my eyes, and I have developed a strategy of dissolving the sting by focusing my attention on it and directing my breath towards the annoying spot. So I have some experience with meditation and pain and thought this was worth exploring.

[A story from my youth about this: During Christmas of 1964, during my Freshman year at Harvard, there was a family dinner in which my Dad was talking about how sensations of hot and cold could be easily manipulated through hypnosis. A person could be given the suggestion that an ice cube was a hot poker, and as a result when touched on an arm with an ice cube, a blister could be raised. Also, with suggestion, you could walk around barefoot in the snow and not feel uncomfortable. Back at Harvard I told my roommates this. They were skeptical. It was snowing heavily outside. I took off my shoes and walked to Harvard Square, strolling about for a half hour or so. Ha, I said. They were convinced. Mind you: I caught pneumonia and was hospitalized for a couple of weeks, and as a result had to drop the second semester of physics -- which I would have struggled with anyway -- and instead took an anthropology class in on "primitive religions" with Cora Dubois in which I read Claude Levy Strauss, my first encounter with French structuralism.]

Back to Bone Marrow Extractions. Marcia's younger sister, Janet Kahn, is a prominent figure in Integrative Medicine. She was on Obama's commission to figure out how to include Integrative and Alternative Medicine into the health care reform. She has a long meditation practice, and so I turned to her to prepare a guided meditation audio that I could listen to. Here is a transcript of the core of the audio.

### **Janet's guided meditation for a bone marrow biopsy**

I don't know if I can promise you painlessness, but certainly with far less pain than would otherwise be the true.

We want to decrease your experience of pain because we want you to be a happy comfortable person.

We are going to do that in two ways.

One is that you are going to say to your body:

I know it is your job to send me a signal when something dangerous is going on. And it makes perfect sense that if someone is boring into one of my bones and taking some of my marrow you would send me a signal "Hey, this isn't good!" and you would send me that signal through pain to get my attention.

The truth is that I have asked for this to take place, and this makes sense because I want to put this episode of leukemia into the past by readying myself for a bone marrow transplant. There are three people that have a perfect match for my transplant. We are so grateful for that and want to take advantage of that. And so I am asking you, my body, to send me a little signal because I want to stay in conversation during this procedure. But believe me when I say I have called for this and I want us to work together to make this as unpainful as possible. So make your signals to me be as gentle and quiet as possible. Know that I am listening to you and honor your responsibility in this episode and also in our whole life together. But I want you to also honor my decision. So, let work together on this.

That is one thing, the signaling. The other thing we want to do is decrease the density in your bones.

Begin by seeing your skeleton in your minds I, your whole boney structure, and tuning into it. Bring your awareness to your skeleton. Begin by saying thank you for all of things you have allowed me to do. All the running, all the standing up and being a human instead of just soft tissue. Thank you for giving me form and motion.

When you are done being actively grateful, then focus your attention to that small area of your sacrum where they are going to go in for the biopsy. What I want you to do here is to recognize that your sacrum, like the rest of your skeleton, like every living thing on this planet, has vibration to it and has space between all the molecules and cells. As solid as everything looks and feels, nothing is absolutely solid. Everything is actually mostly space with levels of vibrating activity. And as you see that and see the space between cells in your sacrum, in that small area – at most an inch in diameter – what you want to do is let the space between cells increase. The cells don't get smaller; they just move out a bit. One image that works for me is a beautiful cumulus cloud. As solid as that cloud looks, we know it is mostly space. You know that at some point that cloud will disperse. That is not going to happen for a long long time for your sacrum. That only happens when we're really gone.

We're just going to allow the space a softening, a spreading in the sacrum itself. You can imagine the needle penetrating not with a lot of push, but penetrating because things are moving and allowing it to come through – like the parting of the waters or the parting of a crowd. See that happen. Feel that happen. First in practice sessions and then in the real time of the procedure. When that happens, just give thanks to your body for allowing that. .... Give tanks for your body wisdom.

### **The procedure today**

So, I listened to this tape four or five times and also practices the inner thoughts while meditating. Today at during the preparation phase of for the biopsy, I listened again. I then began slow, deep breathing, invoking the images from the guided meditation and many of the words. The images were a bit silly at times: My thanking the paid receptors in my scrum appeared as me giving a lecture in a large lecture hall filled with neurons sitting in the seats. A bit hokey, no just doubt.

But it worked. The procedure was nearly pain free. The most painful thing was actually a crook in my neck from lying flat on my stomach with my head turned to the right. There was a kind of shadow of pain just below a threshold of sensation, and an odd shuddery kind of pressure that never was really uncomfortable. I still wouldn't, as Irving Zucker says, "press a bar for it", but the experience today didn't create the anticipatory dread for the next procedure that happened on April 4.

## Comments

Erik, That's so interesting about your Dad's specialty in hypnosis and your own transition into forms of meditation for pain. Mostly, though, I'm glad you got through yesterday and I'm of course hoping for good results. Susan

—*susan friedman, May 1, 2018*

Ah - I had no idea you had this background in breath, pain management, mind, etc.! Wonderful story about you and your dad.

—*Jody Whelden, May 5, 2018*

## Untethered!

*May 1, 2018*



There comes a point in the protocol for this phase of treatment for acute myeloid leukemia when you become permanently tethered to an IV pole. This happens once your immune system has declined to the point that you begin getting more or less continuous drips of preventive antibiotics. For me this was after about week.

Then comes the period of being tethered. One adapts. The impedances are not that big a deal, an annoyance more than anything else. But annoyances are annoying. Two things intrude on your life.

First, the IV needs to be plugged into the wall. It has a battery with several hours of battery life, but the medical staff want the machine plugged in whenever possible. This means that as you move from one place to another in the room -- from bed to "work station" to bathroom to couch to watch an episode of Game of Thrones with Marcia -- you need to unplug and replug the pole. And you have to remember you're tethered so that you don't just absent-mindedly get up and get yanked on your IV line as you walk to a different part of the room. Also, when I would go for walks in the corridors with Marcia (walking is strongly encouraged as therapeutic -- but also there are the 210 laps of the corridors I need to do for the bone marrow-thon t-shirt!) I have to push the IV pole in front of me and inevitably I kick the base from time to time. If I hold it to the side inevitably it bumps into something from time to time.

Second, you can't wear a t-shirt anymore because there is no way to take it off without disconnecting from the IV machine. This why patients shift to the conventional hospital gowns with their complex systems of snaps on shoulders and sleeves. Perfectly good solution, except they're floppy, sometimes a bit uncomfortable (especially at night), and not much of a fashion statement. When Rob Mare and Judy Seltzer (former colleagues in Sociology at Wisconsin who subsequently moved to UCLA) learned of my illness they ordered a couple of these t-shirts for me. Rob had a stem cell transplant a couple of years ago for AML, so they were very tuned in to life during extended hospital stays. They called to ask me whether my PICC line was in my left or right arm. Left I told them. They ordered the shirts. While the shirts were in transit I developed inflammation around the line because of a small blood clot, so the line had to be changed to my right arm. We solved the problem of the wrong-sided snaps by turning the t-shirts inside out. Now that IS a fashion statement. (see the photo of me in the PICC t-shirt)

Well, yesterday I was untethered. Free at last. I can move freely about the room. Unencumbered strolls around the ward -- we did 11.5 laps this morning (to even things out after doing only 8.5 yesterday), about 1.4 miles. Back to ordinary shirts.

## A moment of trepidation

*May 1, 2018*

Sometime later today we will find out the results of the bone biopsy. The possible outcomes are not binary:

- I am in complete remission from the active disease, in which case I stay here for another week and then go to Madison while the preparations for the stem cell transplant take place.
- I have partial remission, in which case we do another round of what just happened.
- There is little remission, in which case a whole new strategy has to be pursued.

Obviously we want the first of these. The second would not be catastrophic, but would be disappointing. The third seems more like a harbinger of bad things to come. And so, this is a moment of trepidation.

I have had pale versions of uncertainties while waiting for medical test results -- will my cholesterol levels be in better balance? Have my diet changes affected my fasting glucose levels? But this is a whole new reality, a reality that every cancer patient experiences. Tests and waiting to see the results. How are the "numbers" behaving? Does this signal a return of the disease? My colleague Doug Manard studies the fine-grained social interactions at the moment of revelation of "bad news": what doctors say, how patients respond, how this delicate and difficult communication is handled in the micro-setting where it is lived. I guess I have had a couple of bad news moments in my life -- the belated news that I had had a heart attack six weeks after it occurred in 1993 and of course, the diagnosis of leukemia on April 4. But this is the first encounter with what becomes a routine fact of life for people with cancer: waiting to see what a test reveals, knowing that much rides on "the numbers." It is hard to experience this just as cheerful anticipation. Possible futures intrude on the present moment.

## Comments

I am waiting. We are waiting with you. Much love. Read you this evening. I smashed my car and spent the whole morning trying to see if they can fix it. I just so hope they don't total it. I feel so ashamed!

—*Magali Larson, May 1, 2018*

I'm on pins and needles, too!

I know you said you prefer emails to comments, but it feels strange to change medium when you're responding to a point. And I don't have anything particularly new to add; I'm just enjoying keeping up with this journal.

—*Betseygail Rand, May 1, 2018*

I am glad that I am accidentally reading your journal backward today, because I already know that this worrisome testing turned out just great!

—*Maryanne Schiffman, May 2, 2018*

## Medical Update

*May 1, 2018*

I just received the bone marrow biopsy report with the best possible result: the bone marrow is completely "empty", meaning that there are no detectable signs of leukemia in the marrow. I had previously incorrectly thought that this meant I would be judged in complete remission. The test for that -- another bone marrow biopsy -- will come once the blood counts in my peripheral blood stream have recovered, probably sometime in the next 2-3 weeks. So, there are more moments of trepidation to come, but for the time being, this is the best possible news. Big Bird from Sesame Street (who I often quote on this) once said, "The Best you can do is the best you can do." Well, "the best possible news is the best possible news."

## Comments

I wish I could say thanks god. Thanks to your constitution, modern medicine (when it is reasonable) and the love that binds us.

*—Magali Larson, May 1, 2018*

So far so good! Happy to learn of this first positive step .

*—Lewis Leavitt, May 1, 2018*

Hurray!! Such wonderful news!! big hugs xox

*—Devah Pager, May 1, 2018*

Yay!!!!!!!

I've been watching for this news along with so many others. What a relief!

*—Mary Jo Maynes, May 1, 2018*

so happy to hear this, Erik!! Keep it up!!

*—Judith Leavitt, May 1, 2018*

Pleasure to be able to join this chorus! Hip Hip HOORAY. This really is fantastic news.

I am sure that you were steeled for the worst possible news, so it must be tremendously elating to get the best possible news instead. Keep up the good work! Big hug of solidarity.

*—Peter Evans, May 1, 2018*

Fantastic news, Erik. The ordeal isn't over, of course, but at least now you can move to the next fight.

—Vivek Chibber, May 1, 2018

I am so jubilant - Fantastic news, Erik!! Big Hugs from the Havens Center (right now)!

—Masoud Movahed, May 1, 2018

This is the news we were all expecting to hear.....That is so fantastic. You rock!!!

—Isabelle F., May 2, 2018

Yes - joining the chorus. Hoorah!

—Jody Whelden, May 2, 2018

Truly excellent news, Erik. Onward and upward.  
Hillel

—Hillel Steiner, May 2, 2018

Wonderful news Erik! So glad to hear this!  
Sending big hugs from Madison.

—Maryanne Schiffman, May 2, 2018

Great news. Keep it coming! Big hugs

—Tom Malleson, May 2, 2018

Oh yes, fantastic news!!!! I love reading this journal and hearing about your journey through this. You are such an inspiration Erik. Love and hugs to you and Marcia. xxx

—Janeen Baxter, May 3, 2018

Such a positive news. I wish the next test could still get good result.

—Lefeng Lin, May 4, 2018



## The 8CFAC Ward: some sociological reflections

May 2, 2018

The ward on which I live is located on the 8th floor of the Center for Advanced Care (8CFAC) in the Froedtert Hospital, associated with the Medical College of Wisconsin in Milwaukee. This has been my home for three weeks and will be so for at least one more. It is a little social world.

I don't know much about hospitals as social worlds in general, or the character of variations in the social organization of different sorts of wards. I imagine that in most hospitals, wards for acute leukemia and stem cell transplants are organized quite differently from most other hospital wards, since the patients on such wards are there continuously for stretches of 4-6 weeks. This poses special challenges. So perhaps what I find remarkable here is just a variation on standard practice.

In any case, I have found the organization of 8CFAC wonderful.

The nurses and their assistants work as teams on what they call a 70/7 schedule: seven ten-hour shifts followed by seven days off. Each nurse has only three patients. This creates strong connections between nurses, CNAs and patients, and gives patients a real sense of continuity of care. We get to know our nurses and they get to know us. They take time for banter and personal conversations. One of my nurses is a super Game of Throne Fans. We've talked about plot points and why it is a compelling series. She pointed out some interesting aspects of the narrative structure that I hadn't noticed. Another shared a ribs with sauerkraut recipe (which I discussed in the posting about Bobbie O). *I feel known by them*. My experience is not what Arlie Hochschild describes as the "managed heart" of worker required to do emotional labor and put on a cheerful disposition and seem concerned about each "client" regardless of what they feel inside. This is much more in line with the qualities of carework at its best, where the setting encourages something closer to an authentic relation between real people who have names and are known to each other, rather than a structured relation between incumbents of roles.

I have had the same experience with the doctors who are overseeing my care. They all take time when they see me not just to give me good information about what is happening, but to listen to me and to engage in the kind of small talk that is so important to positive bonds between actual people rather than just the fulfillment of responsibilities attached to roles. They never seem impatient to leave or that they have more important things to do.

From a sociological vantage point, what all this brings into sharp focus is the contrast between the two faces of any sustained interaction between people within a social structure: (1) The way

those interactions follow a well-defined script assigned to the roles, and each concrete person within their role plays their part by following the protocols of the script. Variation is mostly in terms of competence to play the role well, since of course this takes skill and practice. There are nurse roles, doctor roles and patient roles. The roles are defined by relations, three in this case: nurse/doctor, nurse/patient, doctor/patient. (2) The way those interactions are constructed afresh by the actual, concrete persons within the roles. There are rules (especially norms), of course, which define constraints on this process. But still, within those constraints the named persons can construct inter-personal relations not just enact inter-role relations.

Another way to say this: the actual relations in play are both socially constructed and personally constructed. This is a micro-setting version of the classic structure/agency "problem" (to use overblown sociological jargon). Structured social relations never fully determine how people actually act within those relations; there is always some space for "agency", for self-determined initiatives by the persons within those relations. The actions of people both reproduce those relations -- they enact the relations -- and creatively act within those relations. (enough abstract sociologizing!)

Those are general ways of thinking about roles and persons. Perhaps one way of thinking about variations in social organization in various institutional settings is how narrowly the first face of social relations defines the space for the second. I am sure there are hospital wards in which the rules and norms that define the roles heavily constrain the creative personal construction of bonds and connections between the actual people in those roles. But in my ward, 8CFAC, the institutionalized role relations seem to facilitate rather than obstruct the creation of meaningful personal relations. I feel I am known as a real person by the people who are taking care of me and that I know them as well. My experience is being cared for by people I know and like, not just by professionals who know how to do their job well.

Of course, my "participant observations" here are quite narrowly grounded in the specific experiences I am having, and since I am very chatty, have interesting things to say and am always eager to foster personal relations, my experience could be very different from many other patients. And in any case, some patients might not want the more intimate connection, or not be able to form them because of their own socialization or anxieties. Still, after three weeks here I think that there are reasons to think that my experience is not deviant because of my own creative construction of relations, but something enabled by the stable features of this ward.

I'm sure the high staff-to-patient ratio helps a lot, and probably the 70/7 schedule. The team structure of caregiving is probably organized in such a way as to facilitate good quality communication among the different participants in my caregiving, although don't really have good enough evidence about this to make a judgment. The spatial organization of the ward

seems helpful, with work stations for nurses close to the rooms where they have patients. When I walk the corridors doing laps for my marrow-thon, I often see small groups of staff talking to each other. Once I counted the number of such groups in which there was active laughter as I passed by; three were laughing out of, I suppose six or seven groups. That seems like a high rate of laughing at any one five minute period. The laughs-per-minute in a social setting isn't a bad indicator of conviviality, good feelings, a spirit of cooperation.

It would be interesting for someone to do a serious study of the culture and social practices of this ward compared to other wards in this hospital and an other comparable ward in a different hospital. It would be good to figure out the extent to which my very positive patient experience here is broadly shared by others, what features of the institution in which the ward is located make this possible, and what broader social forces explain variations across hospitals.

## Comments

Great analysis. Having been a hospital chaplain I found it especially interesting to read this account from your patient/professional perspective. It reminded me of a unit where the head of the unit was a very grim faced and almost wordless person. The effect on the staff was profound. Going to visit the unit was always a time for girding oneself, as it was not a welcoming place. I liked reading your analysis of the many levels of relationship and how they interact with each other.

*—Jody Whelden, May 3, 2018*

Erik what a delicious lemonade you have made from the lemons you have been dealt !

It does sound that you are in a really well-run hospital unit with great esprit de corps.

Your chatty positive vibe, no doubt, adds substantially to the job satisfaction gleaned by the staff. Your reward , we hope, will be a successful course of therapy.

*—Lewis Leavitt, May 3, 2018*

## Post-trepidation

*May 2, 2018*

Yesterday was my first known-in-advance Good News vs Bad News event. That is the specific form of the experience: you know in advance that you are about to get information that could drastically affect your life. The prospect of the bad news is obviously the source of trepidation. The trepidation is focused, not diffuse -- not just a general feeling of foreboding, but a focused feeling of dread. I tried to keep this feeling muted, to think myself through it, to bracket the thoughts of negative outcomes. I imagine these efforts helped some, but still the trepidation was there.

The relief was instant. A sense of physical relief washed over me, which makes clear the level of tension generated by the extended anticipation of the Good News vs Bad News event. The bone marrow biopsy was Monday noon; the good news was about 2pm on Tuesday: my bone marrow had no detectable leukemia cells. A day of hard to fully dissipate anxiety.

I know, of course, that this very positive result -- the best news possible at this stage -- does not imply clear sailing ahead. But it feels more like that than simply passing one of the many tests ahead. I'll go with that feeling rather than talk myself out of it to a more sober assessment.

## Comments

Good news about the good sailing so far—hoping for more good winds! Susan

*—susan friedman, May 2, 2018*

I'm delighted that you're delighted. Please let us know what is the good news.

*—Dan Hausman, May 2, 2018*

I'm glad there is good news whatever it is. Hoping for more...  
Janeen

*—Janeen Baxter, May 3, 2018*

Thanks for your generosity in sharing your journey - whenever the spirit moves. I was very moved by your description of good news-bad news 24 hours.

*—Jody Whelden, May 3, 2018*

So delighted to read this piece of the good news that I am going to "break a walnut with my tail," as easily excitable Iranians would say.

—*Mansoor moaddel, May 3, 2018*

Excellent news! And glad to hear your description of this joy.

—*Myra Ferree, May 4, 2018*

## More sociological reflections about the ward

*May 3, 2018*

After I wrote my thoughts about some aspects of the social organization of the 8CFAC ward, I had an interesting hallway discussion with one of the supervisors on the ward. He filled me in on some details. This is a very new ward -- they moved into this building only two years ago. It was the result of merging two previously quite separate units, the hematology oncology ward and the stem cell transplant ward. For the year before the move into the new building, there was a lot of planning and discussion about how to merge the two units, which had different ways of doing things, but overall this seems to have gone smoothly.

I told the supervisor how impressed with the ward I was from the vantage point of a patient and shared a bit of my analysis. I asked what he thought were the key things that created such a caring, patient-centered process. He mentioned the 70/7 schedule which made it possible for patients to get to know specific nurses and nurses to know their patients. But he added two other things.

First, the supervisors on the ward pay a lot of attention to the fit between a potential new staff member on the ward and the culture and routines of the ward, and so they have a pretty extended probation period before making the position permanent. This is really a two way matching process, he said, since not all nurses and CNAs feel comfortable on the ward. Not having a good fit doesn't mean being fired from the hospital, but just not working on this ward.

Second, they have regular meetings on Mondays and Fridays in which people in the various roles within the teams meet to discuss issues around patient care and processes. He felt that these discussions helped facilitate good communication across different kinds of roles within the ward, and fostered mutual respect.

I asked if there was any more explicit effort to articulate the values and norms that guided the life on the ward, basically to transmit the culture through explicit messages. It doesn't seem that that is the main thing. The socialization into the ward's culture comes more from senior staff modeling the ways of interacting with

patients and each other, and then attention to the fit of new recruits.

## Comments

Interesting that they have the option to select and not make the non-selected worse off. With biweekly meetings they have a lot of opportunity to model discussions but I wonder about how observable to each other the interactions with patients are.

—Myra Ferree, May 4, 2018

## More on writing while in the hospital

May 4, 2018



In the first few days after my diagnosis, I began clearing my desk of all obligations and making sure that good arrangements were in place for anything that I had planned that affected other people. Fortunately, in the few months before all this happened, I had managed to finish four or five promised essays and papers, so I only had to cancel one writing obligation. By the time I entered the hospital on April 11, my to-do-list with deadlines was empty. Imagine that.

I settled into the room and set up a work station. I didn't know how physically sick I would eventually feel, and

for sure nausea, headaches and fevers massively interfere with writing. But at the outset, I felt fine, pretty much without symptoms. To my surprise -- and enormous relief -- except for one episode (described in the posting on First Skirmish on April 21), I have felt pretty good throughout this first phase of my treatments.

The result has a kind of writing vacation. In summers for decades I have spent a month or so at Marcia's family cottage on Torch Lake in Northern Michigan. My routine there is generally to write for 3-4 hours in the morning, then bike and hang out the rest of the day. I have found this routine perfect for me; some of my best thinking and writing has occurred at the cottage without me ever experiencing the writing as "work". Well, here I am for a month or so on a vacation with Marcia in an eighth floor room with a wonderful view of Miller Park and the city of Milwaukee and no obligations. Occasional interruptions for orthostatic vitals, medications, doctor's rounds and the like. And instead of biking I do 10 laps of the corridors (1.25 miles) towards my marrow-thon. Still, that leaves me hours of open time for writing. This has given me much pleasure and peace.

At the outset, there were two sorts of writing I had in mind: writing a journal, and working on the final chapter of the book on which I have been working for a couple of years, *How to be an Anti-capitalist for the 21st Century*. The chapter is on "Agents of Transformation," and I pretty much know what I want to say in it. The other five chapters in the book are in good shape. While they could use another pass, I am happy with them and are basically in publishable form. So, I thought in my realism mode: It would be sad to have a posthumous book published with five chapters and then the note "here the manuscript breaks off" when I could pretty easily get a good enough draft of the final chapter. So maybe I should put my mind to it and write that chapter while in the hospital. But I discovered once I started writing postings for the blog that this is what I needed to do now, and so the book was put on a back burner.

I am experiencing the daily writing stimulated by my illness exhilarating. While I am writing, I feel connected to specific people who I know will be reading my posts, so it feels in some ways more like writing a letter to a friend than essays for anonymous public consumption. Writing continually helps me deepen my grasp of the experience I am having. Writing has always been the way I sort out ideas. It is never that I have a fully refined conceptualization of some issue and then write it down; I experiment with strategies of clarifying things through writing. And when everything clicks into place generating a new insight that I feel gets to the heart of some problem, I feel elated. That experience has occurred frequently for me in these days. So, the decision to put aside my book and focus on my journal was a good one, certainly for me.

A few days ago, when I was writing about the 8CFAC ward, my writing wandered into some abstract sociologizing about human agency. There I was concerned with the specific way in which in the micro-setting of the ward, the roles people occupied allowed for the kind of creative, co-creation of meaningful relations between people that I think as contributed to such a caring environment. Writing about agency in that micro-setting triggered my preoccupations



in chapter 6 of the book, which grapples with the problem of collective agency. And so, my thoughts drifted towards my other writing task. I reread chapter 5, which sets up the problem of chapter 6 and looked at my notes for chapter 6. I had only written one paragraph introducing the theme of the chapter:

In some ways, the most vexing problem for the strategic vision of eroding capitalism is how to create a collective actor with sufficient coherence and capacity for struggle to sustain over time the project of emancipatory transformation. It is not enough to have a solid diagnosis and critique of the world as it is and a compelling account of the desirability and viability of alternatives that would make the world a better place. It is not even enough to map about the strategies that would move us in the right direction. For those alternatives to actually be achievable, there must be agents of transformation capable of bringing them about using those strategies. So, where are these collective agents?

That night I fell asleep thinking about the strategy for the chapter, how to frame the problem of agency for the specific context of system-transformation, how to avoid unnecessary complexity, what should be the punchline of the narrative. I drifted off to sleep, dreamed about the text at various times during the night. And then yesterday, sat down and began work on the chapter. Marcia was spending much of the day in Madison taking care of various things, and no visitors were slated to come, so I had uninterrupted time to return to the topic. I experimented with several strategies for posing the problem, and wrote almost 1000 words. This morning I woke up with clarity that the strategy I had adopted wasn't quite right, but I know how to solve it.

So, now I will be writing on both modes -- my journal and my book.

## Comments

It's very cool to hear/read this for a number of reasons. First, because it means you will write that all-important Chapter! (I say as someone who has been struggling with a recalcitrant final chapter for a long time now -- also about rebellion but in the past rather than the future). But also because of what you have said about the different modes of writing and how they work and eventually speak to each other. I love that. I think I mentioned in an earlier post that, coincidentally, I have been working in a research collaborative this year called Narrative/Medicine. (Long story, but it began when I prepared a presentation a few years ago for a Medical Humanities class.) Interesting in all sorts of ways, but I am reading/thinking about your writing in that framework among others. This morning, I went to a workshop centered around the story of Michael Bischoff,



who has been working with friends and colleagues in a group called Healing Story Collaborative at <http://www.healthstorycollaborative.org/index.html>. It was a wonderful event, and the group does post some of the stories on their site, so Michael's might appear there as well. You might want to post something there? They work with CaringBridge too.

—Mary Jo Maynes, May 4, 2018

Yes Erik! I am going to love that chapter (no pressure intended). I remember that the question about the type of collective agency needed for transcending capitalism appeared many times during your presentations in Argentina (2015). In the Latin American context many people also wondered about the potentially violent repression against such a movement. I am sure the book will be very wellcomed here!

—Rodolfo Elbert, May 4, 2018

## Notes from the beginning of this saga

May 4, 2018

Before I started posting entries to my web journal, I had been keeping some notes for a conventional journal of my experiences. Since the blog itself only begins on April 19, I thought I might as well include these early notes:

### Wednesday, April 4

Went to the lab first thing this morning to get tested for sodium balance connected to my diabetes insipidus. Got a call later in the day that the Sodium was fine, but the lab results needed to be sent to Hematology because the Platelet count completely out of whack: 700,000 instead of a normal level of 200,000 or so.

### Thursday, April 5.

Dr. Ciske calls me in the afternoon to say that he has bad news. There are anomalies that look like leukemia. He refers me to hematology oncology. They call for an appointment for Friday for a bone marrow biopsy.

### Friday, April 6.

First we met with a senior fellow. She says she doesn't think I am a candidate for a transplant. Too old. Had a heart attack. I pointed out that this was 25 years ago; there was no functional damage; and the underlying lipid condition was completely under control. But it was a heart attack, she says. Dr. Williams later says I am an

excellent candidate. He confirms the leukemia as acute and probably myeloid. I get a bone marrow biopsy. It was tolerable, but quite painful. Dr. William asks me about the character of the pain, saying he has done 3000 of these but never had one done to him. I describe it by saying: put pressure on a finger on your forehead; move it around in a circular motion; increase the pressure as hard as you can and it will begin to be painful; then imagine that doubled.

Two hours later: we get a call confirming the suspected diagnosis: acute myeloid leukemia. On Monday we'll get a more refined diagnosis.

## **Weekend, April 7 & 8**

Friday night and the weekend, making lists, canceling plans, setting in motion our doctor network for information. I finished editing the conclusion to *Legislature by lot* and wrote the *Preface* to the *Politics & Society* special issue on the subject. That wrapped up all of my writing obligations with any sort of deadline.

Many calls over the weekend: My basic concern is to immediately inform everyone for whom my condition will directly affect their plans. Feeling pretty rational and calm, but just below the surface there is great emotional intensity. Especially when anything connected to my children and grandchildren come up, I choke up.

Email sent to colleagues:

I am writing with some bad news: Last Friday I was diagnosed with acute leukemia. This was completely out of the blue – I have no symptoms at all. The suspicion was raised as a result of a pretty routine blood test and then confirmed by a bone marrow biopsy. The exact prognosis and treatment won't be known until the coming week when the full chromosome analysis is complete, but in any case, it is serious. I will be in the hospital for at least a month, possibly beginning as soon as Wednesday for intensive chemotherapy. The doctor says I am a good candidate for a stem cell transplant, which means that a "cure" is possible, but I'll learn more about the prospects next week. I am pretty hopeful, even optimistic, that I will get through this, but I know for sure that this will be a real challenge for the coming months.

I'm feeling fine right now, and will spend the next two days, before I begin chemotherapy, making all of the necessary arrangements for all of you that are immediately affected by this situation. I will follow up this email with more specific emails to those of you with whom plans need to be made.

All the best,

Erik

P.S. I know that sometimes people find it awkward to communicate with people with a life-threatening disease. I just want to assure you that I am a realistic and resilient person and that you should not feel any awkwardness whatsoever asking me how I'm doing or anything else.

## **Tuesday April 10**

All of my doctor contacts said that the stem cell transplant unit at the Froedtert hospital in Milwaukee was preferable to UW hospitals. We managed to get a Tuesday morning consultation with Dr. Laura Michaelis at the Froedtert Hospital in Milwaukee. She was wonderful. Then we saw the head of transplant team, Dr Hari. Everyone wants to know why we're thinking of Milwaukee. In the end, this was an easy decision.

On the way back into Madison we stop by to see my mother, aged 100. This was very difficult – what to tell her. Initially I was going to say I would be in the hospital for treatment for leukemia, but just downplay the seriousness. But we talked to the social workers in her unit and they felt this would intensify her anxiety tremendously and cause a lot of suffering, so we decided I would just say vaguely I would be out of town for a few weeks. Four weeks more or less, but I would call every day if at all possible.

At 6:30 I went to my seminar on Real Utopias to say good bye to my students. This was very emotional for all of us. I said I had no prepared comments, but wanted to share my feelings. I had prepared them earlier with an email:

Dear students in the Real Utopias seminar,

I am hoping that I will still be able to come to the seminar this Tuesday since I don't think I will enter the hospital until Wednesday. So, on that assumption we will be able to plan how to deal with my absence for the rest of the semester. One thing for sure: I don't think I will be able to read through the interrogations and organize the usual agenda – I just have too many things to set straight before I am out of commission for the next two months or so. So, for this seminar, I think what we will do is just go through the interrogations themselves – treat them as the agenda.

Now, for the plans. Here is some of the issues:

1. We should still hold the seminar session with the web designers of Beautiful Solutions on 4/26.
2. We need to discuss the plan for the Real Utopias workshop weekend. I guess I would like it still to happen. A number of faculty have said that they would get involved to help out, and I think there will still be value for both days of the event. But we should talk carefully about this and see what would be best.
3. I will simply give everyone an A for the course, rather than even attempt to read papers. I will give everyone good feedback on your papers eventually, but I just don't know when I will be in a position to do so.

See you – hopefully – Tuesday evening.

During the seminar, I rambled on about how I am approaching the illness, what its initial impact was on me, and my thoughts about academic life. I told them that I had cancelled all plans and obligations for an extended period, but the only thing that gave me a real pang in my heart was not seeing the play my daughter Becky was directing and seeing my grandson Vernie. This brings into relief that love is really what is most fundamental. I talked about love as caring and kindness and generosity and this is also what has helped make my academic life so meaningful. I then gave a soliloquy about meaning in general and meaning in the face of death and why I

find more meaning in life because I don't believe in God. Star dust, matter made living, living matter made conscious, conscious matter made conscious of its own existence and then conscious of its own death. Making meaning in the face of that: life makes meaning. Everyone cries.

Back home by 8. One final stupid task: turbo tax. Marcia had sorted everything. Only two glitches. No royalties from Cambridge – so I made a guess and sent them an email. Then when we ran the error check there was some stupid error connected to Marcia's schedule C for her book royalties from *Maybe Days*. So I deleted the form. Then when we tried to file electronically there was another error associated with Marcia's royalties. There wasn't a corresponding schedule C. It was 10pm. I had to go into the hospital in Milwaukee the next day. All I needed to do was file the damn forms. So I decided to fill in a whole new Schedule-C for Marcia, linked it to her 1099-Misc for royalties. And it worked. We filed electronically. There was something absurd about doing our taxes the night before going to the hospital for treatment for acute myeloid leukemia.

The next morning we got a call saying that the bed would be ready in the afternoon. Marcia did some errands. I finished up last-minute emails and details.

## Day 1, April 11

I'm in my room in the Center for Advanced Care, Froedtert Hospital, Medical College of Wisconsin. It is 7:15 pm. I am hooked up to an infusion machine that is dripping a poisonous concoction referred to as CPX-351 into a Peripherally Inserted Central Catheter (PICC) line that carries the medicine from just below my bicep through a catheter to a large vein just at the top of my heart. Marcia is here eating her dinner. It is very calm and quiet. *La lutte commence.*

Some small impressions:

I was picked up by a transporter to be taken to the radiology department to have my PICC line – peripheral intravenous central catheter that runs from just below my left bicep to a large vein entering my heart – inserted. D'quan was a large, very gentle African American man, about 30 years old. I chatted as he rolled me down the long corridors. I was lying down but propped up. "You know, from this perspective it looks like we're going down hill, so don't let go." He chuckled. I asked him how long he'd worked at the hospital and what he thought about the job. "Ten months. It's alright. It's a job". Coming back to my room after the procedure we came to a door that was opened by pushing a button right next to the door. It was awkward because he was pushing behind the gurney and there wasn't much room. He deftly angled the rounded front end of the railing and nudged the button. The door opened. "Good move. You figured how to do that". At the end of our journey back to my room I commented, "You do a really good job pushing me – nice and smooth, comfortable pace." A pause, then he said, "No one every said that to me. Thank you."

## Day 2, April 12

Marcia says I'm very chatty. Perhaps the steroid from last night. I dreamt about my final chapter of the book and described it to her.

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I had my first ice cream in 25 years.

### **Day 3, April 13**

Marcia in Madison for the day. Brought back various things we realized we could use: bedside reading lights. My ergonomic bluetooth mouse. Electric razor, which I have never used except briefly as a teenager when I decided I didn't like it.

I had my first PT class – interesting, ten stages with various exercises. Half way through I started crying. I'm not sure exactly why; no clear trigger. I find it difficult to put words to the emotions I'm feeling; they don't seem to fit the conventional labels.

### **Day 4, April 13**

Feeling fine. Trampoline still in place as far as I can tell.

I had a surprise visit by Joel. He said he would like to continue our usual routine of a weekly walk on Sunday mornings which we have been doing for 30 years or so. We did five laps as part of my "marrow-thon."

## **Medical Update**

*May 5, 2018*

I'm in a kind of limbo at the moment waiting for some critical elements of my immune system to recover from the chemo in this phase of treatment. The pivotal element are called neutrophils, basically the component of white blood cells that ingest bacteria. I am currently neutropenic, meaning I have no detectable neutrophils in my blood. This is expected. Before I can be discharged to return to Madison, the count of my neutrophils (ANC or Absolute Neutrophil Count) needs to be increasing. There is no completely fixed threshold; the important thing is that the ANC be rising. It is currently zero. Hopefully this will happen in the course of the next few days. Until then, I am in my cozy vacation spot with Marcia on the eighth floor of the Center for Advanced Care, Froedtert Hospital, Milwaukee.

## **Comments**

Shocking news when I heard it.  
Good luck!  
Your spirit is impressive.  
My sister keeps telling me that beaming love toward a friend in distress helps. So vibes are flowing your way.

—David Schweickart, May 5, 2018

## Neutro Phil: My new super-hero

May 6, 2018



Judy Seltzer sent me a photo of a poster in a bathroom at the hospital where Rob was treated for his Leukemia featuring a superhero named Phil, short for NeutroPhil. I'm waiting patiently for Phil to make his reappearance. Phil does amazing work -- when he shows up. He attacks and devours bacteria, a phage of the first order. When inflammation occurs, Phil is there within minutes, maybe sooner, scouring the region for enemies. Pus, lovely, oozy, yellow foamy pus is Phil's work. But for the moment he's AWOL. Admittedly, it's not really his fault.

CPX-351 wiped my entire population of neutrophils, so of course, Phil has no army to lead. But until he can mobilize new forces, I can't return to Madison.

So, each night around midnight I get a blood draw to see what's happening in my blood. The key indicator is the Absolute Neutrophil Count, or ANC. (And I always thought that ANC referred to the African National Congress). And each morning I'm told what my ANC number is. My ANC is zero. No detectible neutrophils. That makes me neutropenic. This is not unexpected, but soon the numbers should begin to rise, and once they hit some threshold I will be considered safe to release back into the world. Meanwhile, I wait patiently, waiting for Phil.

## Comments

Does he require a chimney?

—Vivek Chibber, May 6, 2018

No! Phil and her army use high tech. My guess is that they are hovering up there looking for the right spot to parachute.

—Mansoor moaddel, May 6, 2018

Patiently waiting with you!! (There is no doubt Phil is on its way. The treatment was so radical, let's give Phil the time needed to reassemble his wining team!)

—Isabelle F., May 6, 2018

Yes - good preparation is important. I imagine Phil is working out his plan and strategy so he can be amazing when he arrives.

—Janeen Baxter, May 6, 2018

“I will be waiting here....  
For your silence to break,  
For your soul to shake,  
For your love to wake!”

Phil will come with his army soon, Erik!! We are all patiently waiting with you!

—Masoud Movahed, May 7, 2018

## Some more thoughts on writing this journal

*May 6, 2018*

In the New York Times on **Saturday, May 4**, there was an op-ed with the title "[Everyone you know someday will die](#)." In it, a number of distinguished writers write short essays on the themes of death and dying. When I saw this, my immediate reaction was that I was not interested, right now, in reading what they wrote. I would have been two months ago, but not now. I've always enjoyed reading these kinds of pieces, but not now. I am also not at all drawn to reading what I am sure is a good memoir literature on struggles with cancer or the thoughtful reflections on life and death by gifted writers with a more spiritual bent. Maybe sometime, but not now.

Actually, my reaction is a bit stronger than just "not interested": I felt a kind of aversion to the thought of reading the NYT pieces. I don't think this aversion is because I think these essays will lack good ideas and insights, or even that the insights of others wouldn't help deepen my own. I'm not quite sure what is as the root of my reaction. Perhaps the idea of reading other people's take on these issues makes me anxious that this might disrupt my own sense of calm about the uncertainties and perils I face. Maybe, but I think the main issue is that I don't want to spoil my own internal process of thinking and reflecting on these big issues by having other people's words actively in my head. For now, I want a purer form of internal dialogue within myself (which I do especially by writing) and conversations with the people I love. I hope this isn't just arrogance on my part; but I want the mini-epiphanies I have to by my epiphanies.

## Comments

I have been absent from your diary for a few days ... because I crashed my car and I had a dozen annoying practical things to do.

Erik, you are never arrogant. This is your ordeal, and your epiphanies. It is real. I often go read the reviews of films or plays I liked, but those are not MY events and I wonder how others felt. This is totally yours, and also of those who love you and are close to you now. Why should you read how others feel, no matter how well they write?

*—Magali Larson, May 6, 2018*

I really appreciate this rumination and I take comfort in it.



—Adriano Shaplin, May 8, 2018

## mini-Medical update

May 7, 2018

Neutro Phil (see May 6 story) has finally made an appearance. My ANC (absolute neutrophil count -- the number of the day) squeaked up above zero: 20. Spies checking out the scene. A small, tentative foray, but I'm told this is likely to be followed by steadily rising numbers in the days to come. Bravo Phil.

## Comments

An awesome piece of news, an excellent way to start the day.

—Mansoor moaddel, May 7, 2018

Great news! I love the personification too.

—Myra Ferree, May 7, 2018

yahooo, go go go Phil!!!!

—Isabelle F., May 7, 2018

Super Eric (and Phil!)

—Lew Friedland, May 7, 2018

So pleased to neutrophils make their appearance JJ

—John Posner, May 7, 2018

Qué buena noticia!! Go Phil, and go Erik!

—Rodolfo Elbert, May 7, 2018

## Extra! Extra! Read All About It

May 7, 2018

**Milwaukee, Wisconsin. 8th floor, Center for Advanced Care. Exclusive report.**

**May 7, 9:00 a.m.**

The renowned hematology oncologist, Dr. Laura Williams, just made her appearance and informed the resident of room 8, that she wanted to discharge him today. Even though his ANC count was only 20, well below the target level of 1000, she was confident it would steadily rise and that he would be fine at home since he had had no fevers and was in a very stable condition. The plan would be to have blood draws in Madison on Wednesday and Friday, and then return to the Hematology Oncology Clinic at Froedtert Hospital on Monday, May 14, when more specific plans for the stem cell transplant would be made. Dr. Williams' hope was that the transplant could take place in the next 2-3 weeks. The patient in room 8CFAC-8 said, in an exclusive interview, "I am thrilled and delighted."

### Comments

WOW!! That is the greatest news. So happy for you.

—jeannette golden, May 7, 2018

WOW!! That is the greatest news. So happy for you.

—jeannette golden, May 7, 2018

Terrific news! 20 isn't that far from a thousand. Ask any ethnographer.

—Vivek Chibber, May 7, 2018

Hang in there murshid. I am right behind you.

—Mansoor moaddel, May 7, 2018

WOOOTT!!! So glad. Sharing in your joy!

—Shamus Khan, May 7, 2018

Hooray!

—*Mary Jo Maynes, May 7, 2018*

You've done it again - beaten all records...

—*Michael Burawoy, May 7, 2018*

Wonderful Monday morning news! Love the thought that you'll be back in Mad-Town!

—*Cathy Loeb, May 7, 2018*

Terrific job, PHIL and Erik, what a team!!!!!!!!!! Full gratitude for this wonderful medical team and for your patience and positive spirit, what an inspiration you are.....

—*Isabelle F., May 7, 2018*

Exclusive interviews are the best. LOL. Thanks for sharing with us so we can celebrate with you. Jody

—*Jody Whelden, May 7, 2018*

WOW!! is definitely the word of the day. Hip Hip Hooray for Dr. Williams and her faith in Neutro Phil. We will all be looking forward to the further adventures of Neutro Phil. What a saga. You are doing a great job supporting Phil, Erik. Keep up the good work.

—*Peter Evans, May 7, 2018*

wonderful news!

—*Matt Nichter, May 7, 2018*

Really awesome news, Erik! You will continue to progress through this!

—*Adam Szetela, May 7, 2018*

Fantastic news. Onwards and upwards Phil!!

—*Janeen Baxter, May 7, 2018*

Hooray!

—*Betseygail Rand, May 7, 2018*

## Back Home in Madison

*May 7, 2018*

Back in Madison, lying in my bed, windows open, pleasant spring evening. Marcia is still unloading the car -- we managed to have a lot of stuff in my little vacation home, 8CFAC-8. Jenny, Mark and Safira are here. The hug to my legs from Safira was wonderful.

The scenario ahead, if all goes as planned is:

- two blood draws and lab work-ups here in Madison this week. Transfusions of platelets or red blood cells as needed. Check on the neutrophil counts. I still have my lovely PICC line, so the blood draws are all done that way.
- Monday, May 14, hematology oncology clinic appointment in Milwaukee with Dr. Williams.
- May 15-23. In Madison, three blood draws a week. This routine continues between the clinic visits to Milwaukee.
- Thursday, May 24. All-day Clinic appointment in Milwaukee with the transplant team. A range of tests, Cat scans and other thing to check out functioning of kidneys, livery, heart and some other organs. Probably a repeat bone marrow biopsy to confirm the remission.
- Wednesday, May 30. Another clinic appointment with transplant team to go over the procedure, various consent forms.
- June 6. Return to 8CFAC. Begin intensive chemo to wipe out as much of my hematopoietic stems cells as possible.
- June 12: Transplant day.
- the next several weeks: in the hospital managing host/graft disease problems and infections
- July & August: outpatient clinic visits regularly. We will live close to the hospital in Milwaukee.
- September: if all goes as planned, back to Madison for longer term recovery.

That's the story ahead. The story at the moment is back home in familiar surroundings.

## Comments

Hooray! Welcome back!! And big ups to you and Phil -- Very much looking forward to seeing you!

*—Masoud Movahed, May 7, 2018*

Welcome home! How terrific to be greeted by Jenny, Mark, and Safira. Looking forward to visiting...

—Cathy Loeb, May 7, 2018

Great news! Home is best but don't tax your strength too much.

—Marianne Ahrne, May 8, 2018

Welcome home, Erik! Please let us know if we can do anything to support you or the extended family!  
Becca Krantz

—Becca Krantz, May 8, 2018

Welcome home!! This is so great. hugs!

—Tom Malleson, May 8, 2018

## On being home

May 8, 2018

It is good to be home. Of course it is good to be home.

But there is also some strangeness in being here. In the hospital I was daily confronted with the reality of my illness. Not that I felt miserable, but that I was constantly being monitored, assessed, asked questions. The social organization of 8CFAC meant that this was all handled in a caring way where I got to know my caregivers persons and felt I was a known person by them. But still: I was a patient in a hospital room, sleeping in a hospital bed, often connected to an IV pole. Here I am surrounded by the utterly familiar trappings on my home in which I have lived for 35 years. In the hospital people talk about going back to the "real world," but somehow, the whole situation feels more "unreal" here. I am surrounded by the familiar photos on the wall of my children growing up, the Indian rugs on the wall, the huge round table in the living room, my cluttered study, but my reality is no longer familiar. That reality was more at home in a way in the hospital room, more congruent.

Then there are also practical matters. This morning a sore on the underside of my tongue which had been bugging me for a couple of days was worse. In the hospital it would have immediately been checked out (as it had been a day earlier). A doctor from the tem would have come in, maybe ordered some tests. I would have felt secure knowing that this was being well tended. Here there is no nurse to check in on me. I call the hematology oncology clinic in Milwaukee and leave a message. Dr. Michaelis calls me back a couple of hours

later, asks a bunch of question, reassures me that it was not serious and that I had done the right thing to call, and then calls in a prescription to my local Madison pharmacy. By the time the prescription is filled it is 2:30. No problem -- this was timely enough. But still, I definitely feel more vulnerable here than I did in the hospital.

And, as expected, being here means much more work falls on Marcia. We're not in our tiny little vacation spot where everything is simple and taken care of for us.

Still, it good to be home. Tomorrow is my first clinic visit to the hematology oncology labs here followed by a meeting with a nurse and possible transfusion of blood products if needed. We'll see how seamless is the coordination between Milwaukee and Madison.

## On Tongues

*May 9, 2018*

In recent days I have become much more aware of my tongue. It is the site of the first real, persistent symptom of the treatment for my illness: a large, red and speckled sore on the underside of my tongue, diagnosed as thrush. Thrush is a fungal infection found most commonly in babies and people over 60. It is not terrible, but painful enough to interfere with all of the activities one's tongue likes to do. You have a bit of food stuck twixt gum and cheek. No problem: the tip of the tongue darts to the spot. Ouch. The tongue is much more active in swallowing that I ever knew. Ouch. And speaking of course. Ouch. I'm taking some medicine to fight the infection, and when my neutrophils are back in strength they will enter the fray as well. But for the moment this is definitely a proper Annoying Symptom.

I've spent some time inspecting my tongue in the mirror to see if this raised red welt was expanding or retreating. Looking intensively at your tongue is like looking at some alien creature in your mouth, wriggling about, rearing up, an eel attached to your throat.

## Comments

Sorry to hear about your tongue. I sympathize with you. Allow me to elaborate: Walnut is an important dry fruit for Iranians. Walnut, feta cheese, and quality bread are excellent combination for breakfast. Occasionally, I eat too much of it and often without thinking. It is enough to chew one bad piece to cause annoying soreness on your tongue. The pain follows with the feeling of guilt for failing to control my appetite for the fruit, which reminds me of my mother's admonition on such occasions that "Mansoor if you find a free rope, you don't have to hang yourself!" An episode like this also reminds me of when you explained to me the difference between rationality and meta-rationality, the latter being the course of action one takes in order to remove the conditions of irrationality. In this case, I have come to realize that I cannot dispense with walnut and thus an occasional "walnut revenge" is a small price to pay for the joy of having walnut-feta cheese sandwich for breakfast.

—Mansoor moaddel, May 9, 2018

Yes, isn't it funny how treatment can make you realize all of the functions that every body part has or should have. I'm guessing they've given you a special mouth wash for this, but if they haven't, ask them. I found that it eased the pain a bit. Keep up the good fight!

—Annabel Ipsen, May 10, 2018

## The "Last Time" Cliché

May 11, 2018

I was walking Fibby (Jenny's dog) with Marcia yesterday evening. It was a clear, pleasant May evening filled with spring smells of newly leafed trees and blossoms. We chatted with a neighbor, someone new to the neighborhood who I had not met before. He turned out to be at UW in Applied Economics. We talked about our respective graduate programs and funding issues. Let's get together sometime. Sure, I said, let's do that. The pleasant sort of things one says. Plans for a possible future.

I walked on with Marcia down the alley towards our house. And the thought came crashing in: This could be my last spring of lilacs and budding trees and lengthening evenings. The thought intruded fully formed as the cliché it is. From movie dialogues I suppose, or novels, or TV shows? I don't know. It certainly didn't feel like an original thought-feeling, but like one of the things one is supposed to think in my circumstances. It is true of course: this could be my last season of lilacs. But the specific form of the thought felt like an intrusion, not a reminder to pay attention and relish the pleasures of the moment.

I am acutely aware that what I am experiencing is something being experienced right now -- today, right now -- by countless other people, and many of them are having some of the same thoughts, feeling the same bewilderments, having the same epiphanies and insights. And many are drawing from the same cultural menu of pre-packaged formulations, even formulas, for making sense of what is happening. This is a moment of heightened individual internal experiencing: it is Me who is experiencing This, with my Mind encountering the faltering of My Body. But for all of its embodied individuality, this is also something universal and deeply shared. And one face of that universality is encountering the clichés that the culture provides. So, I should think kindly toward the clichés -- they can remind me of the commonalty of what is happening to me and with so many others.

## Ritual, prayer and being connected

*May 12, 2018*

Two friends, one in Madison and one elsewhere, have told me that they added my name to a prayer at their respective synagogues. As described in an email: "the Refuah Shlema/Mi SheBerach list -- the list of names of those who are ill is read when special prayer is said at a time after the Torah has been read in our synagogue." I was moved by this gesture even though obviously I don't believe in prayer to a supernatural being who would respond to these requests for help. But I do find it meaningful, genuinely meaningful. I think one might distinguish three forms of the use of prayer in this kind of situation: the purely individual prayer -- someone praying to God on my behalf and keeping this fact to themselves; the more collective ritual form of prayer, where I am included with others who are ill; and sharing with me the fact of these prayers. All of these are meaningful expressions of love and concern. The second affirms that love and concern are a collective matter, expressing the reality of a community of support. The third brings me into to that community, even if I know nothing about the specific people within it. This is like what I said about clichés of illness and dying -- this universalizes my individual experience -- but prayer does so in a way that also affirms the universality of other people's worry and concern over those they love who are suffering. The fact that this takes the symbolic form of a prayer to God seems unimportant to me; the fact that it is a expression of the universal need to support a loved one in distress is what matters. And when the specific form of this expression occurs as a public act within a community, it is all the more symbolically rich, for me anyway. So, I will think more kindly about prayers.

## Mini-Medical Update

*May 12, 2018*

My tongue thrush (see April 9) has been completely vanquished. My tongue can now freely dart around my mouth, doing its inspections and food clearing services without hindrance. It is nice to be able to take it for granted once again.

## Comments

So glad to hear this, Erik!! Recalling your astutely detailed enumeration of the wonders that tongue can do last week in your house!

*—Masoud Movahed, May 14, 2018*



## Medical Update: perfect-match donor confirmed

*May 15, 2018*

The Big News is that the coordinator of the transplant team called this afternoon to say that they had a full confirmation that one of the perfect-match donors that had been identified out of the 27,000,000 people on the international bone marrow stem cell donor registry will donate bone marrow stem cells to save my life. We had been told earlier that three perfect matches had been found, and then later that there were two perfect matches. A perfect match means that 8 out of 8 criteria based on DNA have been met. A perfect match is not absolutely necessary in order to have a successful transplant, but it makes things easier. So now we know not only that there were perfect matches for me on the registry, but that one of these matches has confirmed her willingness to give me some of her hematopoietic stem cells. Yes, "her": I will have female stem cells and thus female blood with signature xx chromosomes. How sweet.

This confirmation of the donor also means confirming the schedule I had been told when I was discharged from the hospital last week: Assuming that the leukemia remission is confirmed through a bone marrow biopsy on May 24, I will enter the hospital again on June 6, have five days of chemo followed by one day of "rest", and then have the transplant on June 12. In the detailed scheduled I have been given that is called Day Zero. Four weeks from today.

On the neutrophil front, my ANC has crept up to 260 from 60 on Friday and 20 a week earlier. Steady progress.

Yesterday we drove to Milwaukee for a clinic visit, blood draw, and general assessment of how things are going. .

### Comments

Fantastic news on the perfect match and your progress, Erik! Made my afternoon -

—*Masoud Movahed, May 15, 2018*

mazel tov! Im so happy to hear about your perfect match!! Lots of love to you both

—*Judith Leavitt, May 15, 2018*

That's great news.

—*Lewis Leavitt, May 15, 2018*

This is such wonderful news!! Moving right along ...

*—Mary Jo Maynes, May 15, 2018*

So happy about this news... the donor (so moving!) and the increasing ANC. Steady progress!

*—Cathy Loeb, May 15, 2018*

Vive la solidarité ! Humanity can be so beautiful. This really is wonderful. June 12 will be a perfect day.

*—Isabelle F., May 16, 2018*

That really is wonderful news, Erik. Please post more!

*—Hillel Steiner, May 16, 2018*

Great news, and much love from your left coast family and friends!

*—Martin Goldstein, May 16, 2018*

Such great news!!! So happy for you, Marcia and the rest of your family.

*—jeannette golden, May 16, 2018*

Hi Erik,

I'm thinking of you and sending you love and good vibes. Very much hoping that this works swimmingly!

*—Rachel Schurman, May 16, 2018*

## **Barkley Bear & Mooney Mouse**

*May 17, 2018*



I'm lying in bed resting. Safira, my almost three-year old granddaughter who is visiting for ten days after arriving from Australia with Jenny and Mark, comes into the room.

"Hello Dadoo," she says in her sweet lilting voice.

"Hi Safira. How about a story?"

She smiles.

"One morning Safira was in the kitchen for breakfast. Dadoo was making pancakes." I then rap my knuckles on the side table by the bed: knock, knock, knock, knock.

Safira raises her hands above her head with her palms up: "Who could that be?"

"I don't know. Let's go see". I mime opening a door. "It's Barkley Bear!"

Barkley Bear, in a low bearish voice: "Hello Safira. Can I come in and have pancakes with you?"

"No" proclaims Safira.

Barkley, in a pitiful voice, "Pleeease Safira, can I come in?"

"Yes", Safira says with an exuberant smile.

So Barkley comes in and sits down next to Safira.

knock, knock, knock, knock.

Again, Safira raises her hands above her head, "Who can that be?"

I open the door. "It's Mooney Mouse, Barkley's friend"

"Can I come for breakfast?" asks Mooney.

"Sure," says Safira.

Mooney joins the table.

Then come, with the same routine: Fred the giant Rabbit, Morris the Monkey (who insists on sitting on the table until Safira tells him that he can't), and Ellie the Elephant.

Safira, speaking to Ellie, "You're too big. You can't get in." So Ellie sits on the back porch and sticks her trunk through the window. Safira is a bit indignant: "No, that's naughty." She thinks a bit. "Let's have a picnic."

I continue the narrative: So, Barkley Bear, Mooney Mouse, Safira, Fred the Rabbit, and Morris the Monkey go into the back yard for a picnic. Dadoo brings out the pancakes.

He goes to Barkley Bear and asks, "How many pancakes do you want?"

Safira answers: "Five!"

Then to Mooney Mouse, "How many do you want?"

Safira Answers, "Four."

Then to Safira, "How many for you?"

"Five!"

And so on. Then I announce the toppings: Barkley Bear has chocolate chips and bananas, Mooney mouse marshmallows and syrup, Safira just syrup, Ellie has Peanuts. Sometimes Safira would interrupt to correct me on some detail. At one point the story gets a bit derailed. Safira went to the side table and went knock-knock-knock-knock. "Who could that be?" I asked. Safira replied, "The Big Bad Wolf. Oh no!!!" She kind of scared herself by announcing that the Big Bad wolf wanted to come to the picnic. I tried some ploys saying that the Big Bad Wolf actually was pretty nice; he just pretended to be a BBW. Safira wouldn't buy it. So I just told him to go away and he did. We finished the picnic. Everyone was covered with syrup and so they needed to take a bath. Safira lead the way up to the bathtub where somehow they all managed to squeeze in and get washed off. End of story.

Mooney Mouse and Barkley Bear stories of this sort are the stories I told Jenny and Becky when they were this age, 36 years ago. How sweet it is to be telling them again.

## Comments

Oh, I love this! We still have taped stories you gave us for Robin and Brian that many years ago...

—Cathy Loeb, May 17, 2018

I remember you telling stories, and you taught me some of the keys to telling them: make it about the child, use repetition, keep getting input from the child. This served us well when my friend, Osha, her grandson and I were returning from Tahoe in traffic and had a long, long, long, long, long, long car ride. Osha drove, I told stories and Ananda did the input.

—Elizabeth Whalley, May 17, 2018

## The saga of Rogue Hematopoietic stem cells, part II (continued from April 28)

May 17, 2018

Here is what lies in store for the rogue hematopoietic stem cells:

On June 6, chemical warfare begins in earnest. Throughout the world that is my body, mutant hematopoietic stem cells have been wrecking the bone marrow apartment blocks within my bone cities. Instead of producing nice white cells who do their jobs with enthusiasm and efficiency, they produce sullen creeps bent on mucking up everything. So, on June 6 -- Day minus-6 on the "Schedule"-- the real war begins. Havoc will reign. Shock and awe. Lots of collateral damage, but hey, who ever said war was nice. Epithelial cells, too bad for you. Hair follicles demise: bald is the new normal. Nausea and mouth sores, the price to pay.

And then, after five days of relentless poisoning, a day of rest on day -1. No more poison; just a dose of anti-rejection medication to make life easier for the new healthy stem cells due to arrive on day zero.

Meanwhile, far far away, a kind and loving body-world unknown to me has taken some benevolent medicine to get her bone marrow to shed her lovely hematopoietic stem cells into her blood stream to be harvested for my well being. Her stem cells are responsible, young, enthusiastic, vigorous. They are eager to work, with a strong sense of duty, but certainly unaware of the adventure that awaits them. They are drawn out of their familiar body-world into a pouch and gently processed to separate them from other inhabitants of the blood. Everything is done carefully. They are a perfect match for the mission that awaits them.

Day zero. Transplant day. The new, healthy, loving, female hematopoietic stem cells arrive; their pouch is hooked up to an IV pole; and drip by drip they enter my body. They diffuse rapidly everywhere. What they encounter is a bizarre new world: a blood-world devoid of most of the familiar inhabitants; bone cities with nearly empty apartment blocks. They know what to do. It's in their nature: they find empty apartments and set up house.

But something is not quite right. The space looks OK, but there is something not quite comfortable. This doesn't feel quite like "home". Should we stay? Should we sulk? Should we try to remodel the apartments? Should we make the best of it? Questions, questions, questions. Mostly the new stem cells shrug their shoulders and say, "This isn't familiar, but it is good enough. I've got work to do. Let's get on with it." Good enough: that is what my 100 year old mother says when I ask her how she is feeling. I hope these new stem cells have the same philosophy: this new body is good enough.

Lots to do. Divide and copy. More stem cells are needed. Differentiate into red blood cells, platelets and neutrophils, so that these progeny can thrive in the new body world. Joyfully duplicate and differentiate.

Then these new residents of the collagen-matrix apartment complexes notice something else is amiss. There are nasty neighbors in adjoining apartments. It turns out that the conditioning chemo designed to wipe out the rogue stem cells didn't manage to get rid of them all. Remnants of the mutant forces remain, lurking in the mostly empty bone marrow apartments. The chemical warfare specialists that designed the attack on day minus-six know that they can never get rid of 100% of the defective cells. The problem is that if they use too much of the poisons, well, they don't just kill off the stem cells, they damage other vital organs and can kill the whole body itself. That's me. Not good. And, when you cross the Great Age Divide that puts you into the category "elderly", the risks of too much chemo increase, so the chemo team opts for "reduced intensity chemo". I liked the idea of

high intensity better, but I have been assured that this still works and produces better outcomes for kidneys, liver and heart that have been working for 71 years. It still makes you miserable. But there are more survivors in the rogue population. And so the new healthy, happy, enthusiastic, xx stem cells from far far away have more work to do: they have to produce energetic white blood cells to get rid of these dangerous nasty neighbors.

But here's the tricky part: The new stem cells need to be happy in their new body and not treat the tissue of the host in general as alien and dangerous. That is why the perfect match makes things easier: less likely to have serious host/graft disease. But these same white blood cells need to attack the mutant stem cells that come from the host's body. A delicate balance is needed. Dr. Hari, the mastermind and head of my transplant team, has all sorts of tricks to make this happen.

So, June will be an interesting time. It begins on the 74th anniversary of D-Day with the massive chemical warfare attack followed by Day Zero on June 12 with the infusion of the new Wonder Women Warrior Hematopoietic Stem Cells capable of multitasking and extraordinary balancing acts. And then in the weeks that follow, the simultaneous war of attrition against their nasty neighbors and the beautiful construction of my new immune system to keep me safe in the future.

## Comments

Many, many thanks for this, Erik: highly informative and beautifully written.

*—Hillel Steiner, May 17, 2018*

## Mini-medical update

*May 17, 2018*

I went to the UW Hospital clinic for labs today, to check on the various numbers that define my State of Being as a Cancer Patient. The number of Chief Concern at this moment is the Absolute Neutrophil Count. The threshold for neutropenia is 1000, a level below which you are considered at significant risk for infection. Below 500 you are at high risk for infection. My level was zero for several weeks; ten days ago when I was discharged from the hospital it was 20; last Friday 60; three days ago when tested in Milwaukee, 260. Today: 1,800. That is in the normal range. That means the healthy part of my stem cell immune system making

machinery has gone into full production mode quite vigorously. I'm sure the rogue part is still doing its creepy work, but perhaps still so subdued as to not matter much. Anyway, another target reached. I'm waiting to hear from my hematology team as to what implications this has for what I should and shouldn't do, but in any case it means things are still on track.

## Comments

Yay!!!!!!

—*jeannette golden, May 17, 2018*

That's fantastic Erik. xxx

—*Janeen Baxter, May 17, 2018*

Ditto !!!

—*Hillel Steiner, May 17, 2018*

Hooray!! Wonderful news!!!

—*Masoud Movahed, May 17, 2018*

Again, and to be repeated, what a team, Phil and you! You rock! This humane « machinery » does wonders...

—*Isabelle F., May 17, 2018*

## Extra-Extra Read All About It

*May 18, 2018*

Madison, Wisconsin. May 18, 2018.

On May 17, upon receiving the test results from UW Hospital Clinic, as reported in yesterday's medical update, EOW was delighted that his Absolute Neutrophil Count had increased dramatically to 1,800. Later, he saw that at the very bottom of the test report there was another number: 4% of these neutrophils were "blasts." He therefore wrote to the Hematology Oncology team for clarifications: was there any concern that the ANC

number had increased so rapidly, and what about this 4% blast number? The official reply from Froedtert Hospital Hematology Oncology Team to request for clarifications concerning latest CBC differential test results has just been released:

*RE: Test Results Question*

*Message body:*

*Hi Erik -*

*It is not concerning at all that your ANC (neutrophil count) has gone up significantly. That means that there are lots of healthy cells recovering from the chemotherapy. Early cells (that have not turned into functional white cells) are called blasts. Some times they are leukemic blasts and sometimes they are not leukemic blasts, just early cells slipping out of a regenerating bone marrow (and its not unusual to see blasts reported on a CBC in this scenario). The only true way to tell is by doing a bone marrow biopsy, which we have planned for next week. You can go places without a mask and you can visit your mother. You should still avoid crowds and be diligent with hand washing.*

*I hope this is helpful. Have a good weekend!*

*Amber Essenmacher, PA-C*

On receiving this report, Erik and Marcia both confirm that they are thrilled and delighted.

## Comments

Great news about the mask :)



—Hillel Steiner, May 18, 2018

As are we (thrilled and delighted)! Wonderful that you can visit your mom.

—Cathy Loeb, May 18, 2018

The news just keeps getting better and better!

—Vivek Chibber, May 18, 2018

## The militaristic metaphor: some initial perplexities

May 18, 2018

This morning, in the wake of the encouraging news about my strongly improved immune system, I was talking with Marcia and Janet about my "saga of the rogue stem cells." Janet pointed out how much this relied on the militaristic metaphor of the "war on cancer" and how this created the illusion of me vs the other, as if the cancer wasn't also "me".

Interesting issues here, tapping into big themes about the meaning of "self" versus "others" and the general schema of binary good vs evil Manichean struggles. There is a real disjuncture between the metaphor I have been using to describe this process of healing and health-restoring in my body and the way I think about societal healing and health-restoring. When I discuss criminal justice issues, for example, I am very much in the camp of restorative justice rather than retributive justice. Retributive justice is all about figuring out the appropriate punishments to inflict harm on those who have caused harm. It takes "perpetrators" as sufficiently responsible for their actions that they should bear harmful consequences. Sometimes the idea of deterrence is added -- which is basically a pragmatic, utilitarian issue of what will be effective in preventing crime in the society as a whole -- but mostly this isn't the core moral impulse, which is that the criminal *deserves* to be punished. Restorative justice brackets the issue of deep responsibility for the acts themselves and instead focuses on how to restore people to the conditions needed to move on and flourish, how to heal both parties. Perpetrators of crime have been damaged in some way and need healing too. The issue is not us vs them/other, but constructing the needed repairs of the "we" for mutual well-being, healing.

Can I think of my cancer this way? Is there a collaborative story of the "we" here rather than the me vs cancer? I could easily accept the collaborative idea of me and my pain sensors as "we" in the meditation for pain mitigation connected to the bone marrow biopsy. But is there anything like this for me and my acute myeloid leukemia? If I could snap my fingers and have it disappear I would. Go away. Be gone. But Janet is also right

that the cancer is "me" too. It feels like an alien intrusion, but it is not. Maybe I am just anthropomorphizing things too much, treating my cells as if they were conscious initiators of acts that bore responsibility for what they do. That was certainly my story of the rogue cells: they were like juvenile delinquents, breaking windows and trashing public parks just for spite. But of course, unlike in my analysis of social contexts of such behavior, I treated their delinquency as utterly unredeemable: they couldn't be rehabilitated through counseling and new job opportunities. They needed to be destroyed, treated as a radical other. I don't know if I can really go beyond that binary in thinking about my leukemia. We'll see what further reflection brings.

## Comments

Musing on this seriously interesting discussion... I wonder if and when we get to the point of identifying in some way the specific cancer cells - "your cancer" — the collaborative rather than the destructive metaphors might point in the right direction ...

—*Martin Goldstein, May 18, 2018*

This is such a weird coincidence, Erik! I think I told you or Marcia about the Narrative/Medicine collaborative that I have been co-directing here for a year now. Our most recent session involved two grad students' dissertation projects. One on them (a geographer) was using/analyzing ecological metaphors at play in scientific writing about a particular type of disease management (in this case involving digestive disorders, and experimental treatments like FMT - fecal matter transplant). I asked her the 'meta-question' of the metaphoric frame and precisely the difference between this ecological frame the the "war on" frame that has always been used with cancer. Is this frame different because of the nature of the illness? the time or milieu from which the discourse is emerging? something else?

AND - an even more meta question. How do the metaphors we use to talk about our relationships to our diseases affect the treatments we come up with? and how we experiences the illness and the treatments, etc.

—*Mary Jo Maynes, May 20, 2018*

Erik, you have transformed a life threatening trauma into a series of amazing sagas, unfolding in unexpected directions with every post. The saga of the mutant hematopoietic stem cells is a scary reality that makes us all wish we were close enough to Madison to come by and give you a hug. At the same time, you turn it into a medical/philosophical puzzle that requires reflection.

Is there value in thinking about the rogues, less as an implacable enemy and more as part of a complex bodily ecology that must be accepted as "natural", even while being dealt with in a way that removes you from jeopardy? The question has a distant echo of the frame used in some of Orson Scott Card's better early work in which visions of alien species shift over time. Of course, this is a different kind of story. The necessary outcome is not in question: the rogue hematopoietic stem cells have to be annihilated, quickly and thoroughly. But, since you are both protagonist and narrator, you get to decide what kind of vision of the process is most fruitful and supportive of your efforts to accomplish the job. What way of envisioning these rogues summons up the most resoluteness and energy? Whatever it takes, I am sure you will figure it out and put it into action with dispatch.

—Peter Evans, May 20, 2018

## Working on my book

May 20, 2018

Since getting back to Madison I have shifted gears a bit in my writing energy from the main focus being my reflections on my health to the final chapter of the book I have been writing, *How to be an Anti-capitalist for the 21st Century* (see my post for May 4). This has proven challenging, both because it is hard to sort out the best expository strategy for this chapter, and because I hit waves of fatigue in which I just can't continue. The fatigue hits me like jet lag: my eyes get heavy and I can't focus my thoughts. When tired like that I find it easier to post something about my health on the blog then grapple with the difficult issues in this chapter. But mostly when this fatigue hits, I take a nap.

Still, in the last few days I have made some progress. I've written about 3100 words so far. Most of the chapters in the book are in the 6000 word length, so I am more or less half way done. The biggest problem I am having with the chapter is that I don't have a snappy punchline around which to build the narrative. Usually the way I write theoretical essays like this one is to figure out the take-away message and then build the narrative. I wonder if this is the way stand-up comedians build good jokes: figure out the punchline first and then build up the narrative around it? In any case, what often happens is that I work for an extended period on clarifying the conceptual foundations of the problem, and in the course of doing this, I figure out a fundamental take-away idea -- the punchline -- and then rework the chapter around that. For this chapter I certainly know what is the problem the chapter engages: The strategic idea I develop in the book -- *eroding* capitalism -- requires coherent political action to change the rules of the game of capitalism in ways that expand the possibilities of building alternatives. But to change the rules of the game requires robust collective actors capable of acting politically in a sustained way for this purpose. Where are they? How do you create them?

Since I don't have a snappy answer to these questions, most of what I have been writing is about the key concepts needed for an answer. In particular, I have been discussing the concepts of "identity" and "interests" as the raw materials around which collective actors get formed. I have lots and lots to say about both of these ideas, and that's the problem. Without the punchline in hand, it is harder to know what to leave out. I'm not writing a sociological textbook on the problem of collective action in general. There are all sorts of very interesting issues around the formation of shared identities and interests, including some themes from cognitive psychology, which I give lectures on but which probably don't belong here. So, I keep adding things then cutting them back.

One thing I included, and think will probably stay, is a vignette about a week I spent in Sarajevo in 2007 which

I use to illustrate a key distinction in the concept of identity. It's pretty interesting, so I thought I would share it here:

In 2007, I spent a week in Sarajevo at the invitation of a group of undergraduates at the University who had organized a conference on the relevance of Marx and Hegel for contemporary issues. I stayed beyond the conference and gave a number of lectures and seminars on the themes of my work on Real Utopias. The students were eager and animated. They came from all three ethno-religious communities in Bosnia – Bosnian Muslims, Croatian Catholics, and Serbian Orthodox. They had all lived through the siege of Sarajevo as children and were fed up with ethno-nationalism. They desperately wanted to be cosmopolitan Europeans. By the end of the week, I felt very close to a number of them.

On the last evening we were in a pub together, and I said, rather glibly, “You know, in terms of identity I feel much more like all of you than I do like American Christian Fundamentalists. They seem like they’re from another planet. You are all kindred spirits, sharing my core values and sense of meaning.”

A young woman in the group, early 20s, replied, “This is not what identity is all about. It is not an answer to the question ‘Who am I?’ It is the answer to the question, ‘Who do other people say I am?’ If we were to cross the bridge to the Serbian sector and there was a policeman who saw you get mugged, he would come to your rescue. If he saw me getting mugged, he would turn away.

Later she added, “It is a great privilege for people in rich countries with liberal democracies to be able to ask the question “who am I” rather than have their identities coercively imposed on them. The idea of young adults ‘searching for their identity’ just doesn’t make sense here.”

I then commented: "This story illustrates an important contrast among the many forms identity that are subjectively salient to people: some of these mainly reflect differences among people, differences that matter to them and which to a greater or lesser extent they choose to cultivate, while others are imposed on them by the society in which they live. I had experienced the week in Sarajevo with these students as reflecting our common identity as progressive intellectuals, an identity which is chosen and cultivated over time. They experienced identity as something imposed on them by powerful forces over which they had little control."

I figure I have just over two weeks left before D-Day. As long as I work on this a bit every day so that it is on my mind, then I should have a completed draft by June 5.

## Comments

Some thoughts -- I'm a long way from my sociology background -- but I remember (and use in teaching) the distinction between ascribed and achieved status, and that could be the same for "identity" -- some we achieve and some comes with -- like being white -- or black -- in America.

Social movements are, these days, I think -- the kind it would take to make a dent in capitalism -- would have to appeal to an achieved identity (i.e. "progressive") to move towards socialism, while it seems like the appeal to an ascribed identity often leads towards fascism...

Don't know where to take this, but clearly ( I think) "identity" is a mixture of both. I know when I ask my students, 2/3ds of whom are international, mostly Chinese or S.Korean -- "who are you?" -- they use gender and nationality ("a girl from China") -- then spend the rest of the page describing what they like or like doing, etc -- their personality. To them, that's their main identity, along with (but not necessarily totally controlled by) their ascribed gender and ethnicity.

That's a luxury, as your Sarajevo friends say -- but we live here, not Sarajevo. I don't think it favors large social movements -- not anymore in developed countries -- but I certainly don't know.

Anyway, most enjoying your writing here -- and I loved your kid stories -- that should be a book, too....

Take good care,

Martin

*—Martin Goldstein, May 21, 2018*

## Mini-medical update

*May 22, 2018*

The Big Update will come on Thursday the 24th after I finish a full day of tests, including a new bone marrow biopsy, at the Milwaukee hospital. That will confirm, hopefully, the robustness of the remission from active leukemia and thus give the green light for the transplant in June.

Yesterday I had another regular blood draw at the UW clinics, and once again my neutrophils behaved admirably, reaching an ANC of 2,770, well above the lower boundary of normal (1,700). In early March before the leukemia diagnosis, in a blood test that was trying to figure out the source of my sodium imbalance, my ANC was 1,200, which I now know would put me in the moderate risk for infection zone. So already back then, clearly, the leukemia had depressed my ANC. The chemo in April knocked the ANC to zero, as it was supposed to do. So now it has rebounded to well above the pre-treatment level. This is the sort of thing that you talk about when you become a budding expert-cancer-patient: the subtle movement of numbers, their trajectory over time, what they portend, what might be lurking in the shadows. It reminds me of watching the FiveThirtyEight reports of tracking polls in October of 2016: the magical power of numbers to predict the future.

## Comments

All best to you from your left coast family!

—*Martin Goldstein, May 22, 2018*

Great news!! There will be another great news on Thursday, the 24th, too!!

—*Masoud Movahed, May 22, 2018*

## Suffering, but with privilege

*May 22, 2018*

Having a serious, life threatening disease like acute myeloid leukemia provokes many different kinds of introspection. So far I have not really confronted the dreaded forms of physical suffering that one associates with cancer. Perhaps that will come next month, perhaps not. But what I do know is this: whatever physical suffering I will have will occur in a context of extraordinary privilege that will shield me from much of the terror of such suffering. I will be in a calm and quiet hospital ward with three patients for each nurse. I will have a team of doctors focused on my well being who I trust and feel have lots of tricks up their sleeves both to help me survive and to attenuate the worst symptoms. Marcia will be with me. This is sheltered suffering, suffering muted by privilege. It is the kind of setting in which everyone should be able to live their lives in moments like this. But of course, it is available only to very few people in the world.

At this very moment there are, I imagine, thousands of people around the world with acute myeloid leukemia who will simply die without ever knowing what hit them, with no access to any treatment. There are others in crowded and unsatisfactory hospitals, and no prospect of access to the stem cell transplants which might save their lives. And, outside of the bounds of my own specific illness, there are millions of people in refugee camps who suffer physically and face constant threats of deprivation, illness, despair; others in war zones; and of course, especially, children fully exposed to the terrors of intense suffering without any protection. I don't feel *guilty* for being in the privileged position to survive this illness with muted suffering. Nothing whatsoever about the injustices of the world would be improved if I unilaterally rejected this privilege. This fact, however, does not make my privileged access to the care I am receiving fair or just. It creates a divide between me and others who face in exactly the same way as I do an uncertain hold on life but without access to the care they need. This is a moment when I have come to feel, deeply feel I think, the universality of my experience and the ways this makes me just like other people. But that oneness, that sense of compassionate softening of the boundary of the self, is undermined by the realities of my extraordinary privilege. I'm not quite sure how to describe the emotion this invokes in me, but it is something like grief.

[A side note here -- added after I finished my thoughts on privilege and suffering: Because Medicare pays

hospital bills, the population of people on the acute leukemia ward at Froedtert Hospital is quite inclusive; it is not wealth as such which gets one access to the ward. The unfairness, therefore is not so much about access in the immediate environment to this specific setting, but rather about the the global context of human beings around the world who suffer.]

## Comments

Erik--thanks for these reflections! It brings me, and must bring others, a great sense of peace to see someone negotiating with (to use a non-military metaphor) such an illness to have such a sense of equanimity and care for others.

Also, this pertains to a different post, but I'm struck by your sheer stamina. When you described the fatigue you've been experiencing while completing the manuscript, I thought "this sounds an awful lot like my daily afternoon drowsiness that I experience for no particular reason"--of course, I probably experience it to a much lesser degree, but regardless...your near-boundless intellectual energy is inspiring!

—Griffin McCarthy-Bur, May 23, 2018

## more on metaphors: pruning

May 23, 2018

I have had a number of conversations with people following my post about the use of militaristic metaphors in the treatment for cancer. The military metaphor certainly lends itself to good story telling. It is such a staple template for talking about all sorts of things in which there are goals, obstacles, dangers, conflicts: the war on poverty, the war on drugs, the battle of the sexes. Military metaphors are built into the language of sports -- the offense and defense, the names of mascots. But since I am so resolutely anti-militarist in my political and moral views, it would be good to have other metaphors in play as I deal with my illness.

One idea that came up in a conversation was "pruning". When there is a dead branch on a tree, you prune it so that the rest of the tree can flourish. Pruning rose bushes makes them more vibrant the next season. Pruning is removing something that is part of the whole, not an alien intruder, in order to make the whole stronger.

These thoughts also suggested another thing about my "saga of the rogue stem cells". For obvious narrative purposes, I treated the rogue stem cells and their lively, healthy, young replacements, as if each of these cells was an autonomous living being, not a part of a living being. Indeed, I treated them as if they were willful beings that either behaved responsibly or did nasty things. That's fine for story telling. But while there surely is

a meaningful sense in which we can say that a single cell within a larger organism is "alive" or "dead", it is pure anthropomorphism to treat them as autonomous beings. My mutated hematopoietic stem cells are part of me. They are not a virus from the outside world that has entered by body. They don't have motives and purposes, of course; they just don't work well in ways that are harmful to the whole that is me.

So, perhaps, pruning them is the way to think about what lies ahead. This is also resonant with the task of successfully welcoming the new stem cells provided by my benevolent donor. The difficulty in having them meld with me is called Graft versus Host Disease (GVHD). Pruning and grafting, the work of a horticulturalist making a fruitful orchard. I do like nectarines: half a peach; half a plum; one helluva fruit, as Mel Brooks once said. ([link](#))

[**May 24: A little correction.** After I posted the pruning analysis, I realized that a nectarine is not the result of a graft of plum & peach but of some process of making a hybrid of plum & peach. The Mel Brooks link is still funny.]

## Comments

Love this metaphor, and love you!

—Josh Wright, May 23, 2018

Enjoying very much your postings to us all. Yes, we all grapple with this dilemma of leaving war metaphors out of our lexicon. Nice thoughts on one possible alternative. Pruning does have magical powers, done properly, at the right time of year, for the right purposes. Warmly, Jody

—Jody Whelden, May 23, 2018

I love the pruning metaphor! Only wish I had thought of it. I am glad always to see things going so well for you and the interesting reflections on illness, community, prayer and life. Hope your book work continues to go well and doesn't stress you out. I'm sure it would be totally awesome for this to get done before you plunge into the next stage, but have confidence that it will get done at some point. Prayers for you also coming from this Episcopalian.

—Myra Ferree, May 23, 2018

## Medical Update: the first glitch



May 24, 2018

Well, today's clinic trip to Milwaukee brought some disappointment. The first stop was the lab for a blood draw, then a discussion of some practical issues with a social worker, and then the bone marrow biopsy.

The central issue in play is whether or not the remission is sufficiently robust to continue to the transplant. To definitively answer this question requires detailed analysis of the bone marrow biopsy. We'll have the results of that tomorrow. But some indications can also be seen in the analysis of the blood draw from the lab. One indicator in the blood analysis is the % of white blood cells that are "blasts." Blasts, as measured in the peripheral blood, can be either immature neutrophils or leukemic cells. I was told earlier that it is not unusual to have some blasts in the blood when the bone marrow is "reorganizing itself" after the chemo. So when, in earlier blood draws in Madison I saw blast levels at 1% and then 4% I was told not to worry. Today the level was 7%. That was high enough to be of concern. Everything else looked fine. But Dr. Hari, the head of the transplant team, felt that 7% could indicate the leukemia is rebounding. We'll know tomorrow. For complex reasons that have to do with creating the optimal environment for the new stem cells in a transplant, it is not possible to proceed to chemo associated with the stem cell process unless there is a robust remission.

So, tomorrow there are two possibilities: (1) The bone marrow continues to be empty of leukemia, and so we proceed as originally planned. (2) There is a return of leukemia in the bone marrow, and so we have to turn to "plan B". Plan B itself has several options, including repeating exactly what I did in April, doing something similar to the April chemo but with a different cocktail, or adopting an out-patient strategy with more extended chemo combined with pills. Dr. Michaelis will call tomorrow to let us know.

In the original diagnosis of my Acute Myeloid Leukemia (AML), the chromosomal analysis indicated that my specific mutations put my leukemia in the "high risk" group of AML. Other specific mutations are associated with low or moderate risk AML. I asked Dr. Michaelis today if "high risk" meant precisely what we were facing here: greater difficulty in establishing a robust remission. She said that was indeed the issue. So it goes.

This is not doomsday by any means. There are still pathways to the transplant. A "winding road" is how Dr. Michaelis described it. Of course this is discouraging. The narrative I had been assiduously working on had a series of steps and I was methodologically moving from one to another. Each step had gone smoothly with the "numbers" doing what we had hoped. That simple sequence may now be disrupted; we'll know tomorrow.

## Comments

This is tough, Eriki. Like you, we've been saying ... so far everything is going the way we all wanted it to. This is indeed a glitch, but having a second round of chemo was something always built into your plans as you have laid them out. Thinking of you, and we will see you very soon!

—Mary Jo Maynes, May 24, 2018

I am hopeful that we will have better news tomorrow. You are in my thoughts Erik.

—Mansoor moaddel, May 24, 2018

From across the globe, waves of support vibes coming to you!!!! Keep up with the positive, fighting spirit.  
???????

—Isabelle F., May 24, 2018

Hang in there, Erik. I'm sorry this part isn't going as smoothly as you'd hoped, but hopefully this is just a small bump in the road on the way to a much better path. I'm thinking of you and sending you big hugs. -Devah

—Devah Pager, May 24, 2018

I am sorry to hear about this glitch— but am sure you will defeat it just how you have been defeating the others. Sending you big hugs!! And much love —

—Masoud Movahed, May 24, 2018

Erik -- I'm sorry to hear about this potential setback. Here's hoping that the doctor's call today augurs better! I like the winding road metaphor...there's always something else that can be tried!

—Griffin McCarthy-Bur, May 25, 2018

## On a lighter note: nectarines

May 24, 2018

Well, it just goes to show -- don't take your science from the 2,000 year old Man!

At the end of my post on pruning on May 23, I added a bit about nectarines taken from Mel Brooks and Karl Reiner's wonderful skit, "The 2,000 year old man". I wrote:

"Pruning and grafting, the work of a horticulturalist making a fruitful orchard. I do like nectarines: half a peach; half a plum; one helluva fruit, as Mel Brooks once said. ([link](#))"

I later thought about it, and realized that what Mel Brooks had described wasn't a graft, but a hybrid, so I added:

**"May 24: A little correction.** After I posted the pruning analysis, I realized that a nectarine is not the result of a graft of plum & peach but of some process of making a hybrid of plum & peach. The Mel Brooks link is still funny."

Today, I thought I should check out the Nectarine Story properly. Here's the scoop, straight off the Internet: "A **nectarine** is not a **hybrid** of anything - it is merely a smooth-skinned peach. They've been cultivated as long as furry peaches. A **nectarine** (*Prunus persica*) is a fuzzless variety of peach. It is not a **cross between** a peach and a plum. Fuzziness is a dominant trait of peaches."

Mel Brooks is still very funny. And I do recommend watching the clip from the 2,000 Year Old Man, but alas, he is not a reliable source on the science of nectarines. I should have realized that from his account of the discovery of sex.

## Comments

But he was right about Sara Wrap, wasn't he....?

Hmmmmmm.....

—*Martin Goldstein, May 24, 2018*

## Medical Update: glitch but not derailment

*May 25, 2018*

To cut to the quick: the news from Dr. Michaelis was very reassuring, even though the blasts measured in the bone marrow show that there has been a reappearance of the leukemia. This means the remission is not as robust as hoped for and so we cannot go straight to the transplant process on June 6. Dr. Michaelis reported that Dr. Hari -- the head of my stem cell transplant team -- says that there is a new clinical trial protocol that will "open up" in a month that is specifically designed for someone with my profile, i.e. someone with a significant, but not complete remission. To be eligible, I will need to have a second round of induction chemotherapy (induction was the first phase of treatment that I had in April). Dr. Michaelis said that so far she has only seen the preliminary report from the bone biopsy, but needs the full report before she will be able to make a final decision of precisely what form the repeat induction should take. It could be either in-patient or out-patient, and

either in Madison or in Milwaukee. She will let us know probably on Monday. One thing she made absolutely clear: She is determined "to get me to transplant" and feels this setback is manageable.

So, as far as I am concerned we are back on the winding path, not off the path. The prospect of a transplant is still very likely, and given the perfect match, the prospect of it working is good.

## Comments

thank you for the update. This is not as straightforward as hoped for, but the news are still very positive, and your medical team seems extremely solid so there is not doubt they will get you to transplant indeed. I welcome this as a positive piece of news, even though this means your patience will be tested some more. sending constant positive energy for your full recovery.

*—Isabelle F., May 25, 2018*

I zhall only breathe

*—Magali Larson, May 25, 2018*

Wow, terrific news!!

*—Griffin McCarthy-Bur, May 25, 2018*

As you have noted so many times in your work, there are many paths forward!

*—Adam Szetela, May 25, 2018*

## Fatigue

*May 26, 2018*

I'm grappling with fatigue. Of course there have been many times when I've been tired: sleep deprivation with infants; jet lag that pounces at odd times; an occasional illness that saps energy. But mostly the persistent feeling of being without energy, and especially without the ability to call forth energy when I needed it, is unfamiliar. Last night I was having an extended discussion with Janet, Marcia's sister, about healing, my priorities, how I was feeling, and at one point she commented that I was always a person with "boundless energy." I liked the expression; it struck a deep cord. What came into clear focus was not simply that this was

often true for me, but that also it is a significant part of my self-concept, of my identity in the most personal sense of how I live in the world. (This is not exactly the same as the issue of effort & willpower that I talked about when I was in the hospital, but I suppose they are connected).

Whenever I travel to give invited lectures I tell my hosts to schedule as much as possible -- multiple talks to different kinds of audiences, speed-dating master classes with graduate students, Real Utopian site visits. The more the better. Sometimes this could be quite taxing, pushing my limits. Once I travelled first to Iceland and then to Argentina while recovering from ciguatera food poisoning (a neuro-toxin I ingested when eating a piece of amberjack), which meant that periodically I would itch all over along with other symptoms, but I didn't cancel any of the many events that had been planned and could always mobilize the energy and focus needed for the occasion. I once did a speed-dating-master class in which some 18 students showed up. The routine involves each student getting ten minutes to pose problem/puzzle from their research that they cannot answer and the I try to say something sensible. These interactions are generally intense. I have to listen very carefully to make sense of what students are saying and then come up with something interesting and helpful to say. Even with a timer, these encounters often run over, so 18 "dates" lasted almost four hours. This was followed a couple of hours later with my giving a public lecture. I was, for sure tired afterwards, but never felt my focus or energy level flag during the events themselves. Being like this is an important part of who I am. (And I have to admit -- although this isn't my main point here -- that I also get a lot of pleasure from how impressed everyone seems to be with my "boundless energy." People often comment on my intellectual stamina. I like that this is how other people think of me.)

So, I no longer have boundless energy. I cannot summon it up when needed. Today I sat down at my computer to work on a tricky passage in the chapter I am writing. I know what I want to say substantively, but there is some difficult word crafting that needs to be done. I couldn't mobilize the focus. I can write this blog without a problem, but this does not require the intense concentration of writing an analytically complex argument. This morning I just couldn't do this.

I know this is not going to be a permanent state of affairs. Probably much of it is because of my persistently low hemoglobin count which hovers just above the threshold where I would be given a transfusion. (I think I'll ask for a transfusion next week if this is still the case then). Still, I am finding this difficulty in mobilizing the energy needed for concentrated intellectual focus not simply frustrating, but unsettling. Maybe its time for a nap.

## Comments

Now you know what the rest of us feel like!

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—Dan Hausman, May 26, 2018

Naps are very healthy. Fighting fatigue is not. Picking a priority - self image or better health - seems a no-brainer to me.

—Myra Ferree, May 26, 2018

Dear Erik, I have been reading your posts with great interest and compassion over the last several weeks, with updates from Cathy as well. My heart goes out to you, and I am sending loving energy to you and Marcia daily. Even for someone with limitless energy, stamina, and optimism, what you are going through would be extremely taxing and challenging. It is your body after all, which really is the foundation for everything.

I often have marveled at your energy and optimism, first over the six years of working with you as a graduate student, and then when I'd hear updates about your professional activities from Marcia or Cathy. After reading your latest post, I thought I'd share a recent experience that changed my life. Almost three years ago, I had shoulder surgery which, while necessary, produced a new set of problems that I had never encountered before -- chronic pain and fatigue. While my health situation has been quite minor compared to yours, I found myself able to do far less than before in every area of my life--from career and family to friendships and community. It took me awhile to realize (and then accept) what I needed to do, but eventually I decided to step away from my career. I know this is not an option for you, but I wondered if perhaps this challenging time may provide an opportunity to nurture other parts of your life.

I hope I am not being presumptuous in offering these thoughts. Warmly and with love, Cindy

—Cindy Costello, May 26, 2018

Your journal entries are quite impressive--full of fresh ideas and thought-provoking insights. This is true even for a person without health issues. Please don't expect too much from yourself, number one. Number two, the late spring weather makes everyone drowsy. And number three, we often write more effectively where our attention span is. Your blog is a great work. But try to rest and have as much fun as possible with family and friends.

En route to Cairo with love, Mansoor

—Mansoor moaddel, May 26, 2018

Anyone reading your Caring Bridge blog entries has to see you as a person of "boundless energy," whether or not you feel that way – not only because your posts are so voluminous and continuous, but also because they are so impressively wide-ranging, insightful and original.

By your own standards, no doubt, there is a change, but I am wondering whether the change is "less energy" or it is simply a necessary shift in how your boundless energy is directed. Reconstructing an entire immune system, shifting the demographics of your hematopoietic cells and doing a bunch of other reconstructive internal tasks that I would not even pretend to understand has to be a major project that requires investment of a lot of

energy. Hard to imagine that you can be making investments of that kind without reducing the amount of investment available for normal “external” jobs. “Fatigue” may be your body saying “Apologies Erik, but I have priority things to do right now, so some your other projects will have to go a bit slower for a while.”

Many or most people wouldn’t have what it takes to keep moving forward along the “winding path,” but you do. You have exactly the sort of robustness, resilience, fortitude and determination that I am sure your oncology team finds thrilling and gives them such optimism, and fills the rest of us with supportive admiration.

—Peter Evans, May 26, 2018

You have more energy than anyone I have met, so maybe now you are down to a normal level! But seriously, when I had cancer I wound up getting 3 blood transfusions because my red blood cells were being whacked (and my white cells and my platelets....) The blood transfusions each helped enormously. And napping is a great thing!

—Debra Satz, May 28, 2018

## Medical Update

May 28, 2018

So, there is a new plan in place: a 21-day protocol starting tomorrow consisting of a combination of chemo infusions and pills on some overlapping schedule. This is a protocol specifically designed for someone in my situation: a good candidate for transplant, but not a satisfactory remission with the initial induction chemo. I think the idea is that after this 21-days of new treatments, I would then go pretty rapidly to the transplant stage, but I am not completely sure. I will get the fine-grained details tomorrow afternoon when we go to Milwaukee for labs and the initial treatment and will then share these tomorrow evening.

## Comments

Always thinking and trying to send loving strengthening vibes  
7

—Magali Larson, May 28, 2018

Please know that we are thinking about you and sending love.

Ellen Levitov and Vern Baxter

—*Ellen Levitov, May 28, 2018*

From Cairo with love. From the balcony of my room, I am staring at the Nile and wishing for your quick recovery. You are indeed in my thoughts.

—*Mansoor moaddel, May 28, 2018*

Many hearts holding one heart.

—*Jody Whelden, May 28, 2018*

Sending you big hugs and much love, Erik!!

—*Masoud Movahed, May 28, 2018*

## Medical Update

*May 29, 2018*

I am sitting in a chemo-infusion chair at the Froedtert Hospital Day Cancer Center, currently getting a dose of preventative anti-nausea medicine before the actual infusion of the new chemo, called Azacitadine (trade name Vidaze). A lot of the chemo medicines I see have the suffix "dine". I like to think that is this because they dine on cancer cells. Very tasty. So, here is the plan of action:

1. I will get Azacitadine aka Vidaze as an out patient for seven days. It means driving into Milwaukee every day for a week, but it is only an hour and fifteen minutes door-to-door, so that's not so different from the commute time of many people.
2. This will be combined with 21 days on pill called Lenalidomide aka Revlimid. It doesn't dine on cancer cells. It amides them. (I just looked it up: the suffix amide actually means "Monoacyl derivatives of ammonia". I hope this clarifies things). This is the same chemical that was notoriously used in Thalidomide in the mid 20th century and produced such catastrophic birth defects, so it is now a highly controlled substance. I had to sign a bunch of forms saying that either (a) I would avoid getting pregnant, or (b) use a condom whenever I had sex, since apparently the drug can get into the semen. I dutifully signed the pledge. I will supposedly be contacted by the drug company at the end of the treatment to confirm that I abided by the pledge. This drug is also one that is used in multiple myeloma and I know that my brother Woody is familiar with it from his own cancer



treatments. These 21 days can start whenever I am approved by the insurance company for the treatment, which can take anywhere from a couple of days to a couple of weeks (how's that for stupid!) so the whole cycle will probably take somewhere between 25-30 days (assuming that I get approved for the Lenalidomide, which I imagine will be the case).

3. I then get another bone marrow biopsy to see if my bone marrow is empty of blasts. If not, go to step 5b; if empty of blasts go to step 4.

4. Retest bone marrow once my neutrophils are back in action, probably a couple of weeks later. If there is still a robust remission, go to transplant, step 5a; if there is not a robust remission, go to 5b.

5a. Bone marrow transplant conditioning and then transplant, pretty much along the lines initially planned. This would be sometime in July.

5b. If I do not have a robust remission -- ie. still basically the situation I am currently in -- then I will enter a clinical trial phase III with a new protocol for bone marrow conditioning and transplant that has proved very successful for people like me with an aggressive acute myeloid leukemia with a "5q cytogenic abnormality and a myelodysplastic syndrome". This is a phase III trial, which means it will be random whether I initially get the new treatment that had nearly 100% success rate in the Phase II trials, or I would get the standard treatment that I would have gotten in then absence of the new strategy. IF I am allocated into the control group and IF that treatment doesn't work, then I will be given the experimental treatment. So, not getting the clinical trial experimental treatment initially does not mean I would be excluded from it; it only means a delay if the standard treatment doesn't work. This would also be sometime in July.

So, this is all a bit complicated. There remain contingencies and branch points. The goal remains the same: a bone marrow stem cell transplant. If the new schedule holds, then this should occur sometime mid-late July I think.

## Comments

thanks for the update! clearly a complex path but at least a real one with promise to get you where you want to go. Good luck!

—Myra Ferree, May 29, 2018

Thanks for keeping us posted, Erik!

—Christine Schwartz, May 29, 2018

As energy-draining as this process is, I am certain you will get through and defeat it. Your inspiration is eternal, Erik! big hugs —

—Masoud Movahed, May 29, 2018

You

—John Posner, May 29, 2018

Again, many thanks for this, Erik.

—Hillel Steiner, May 30, 2018

Thanks for these updates, Eriki! It's good to hear you explain the various possible paths of treatment, including the (sooner or later) access to the experimental treatment. Thinking of you! Teresa says hi - we had a writing hunker this morning and she was asking about you and Marcia.

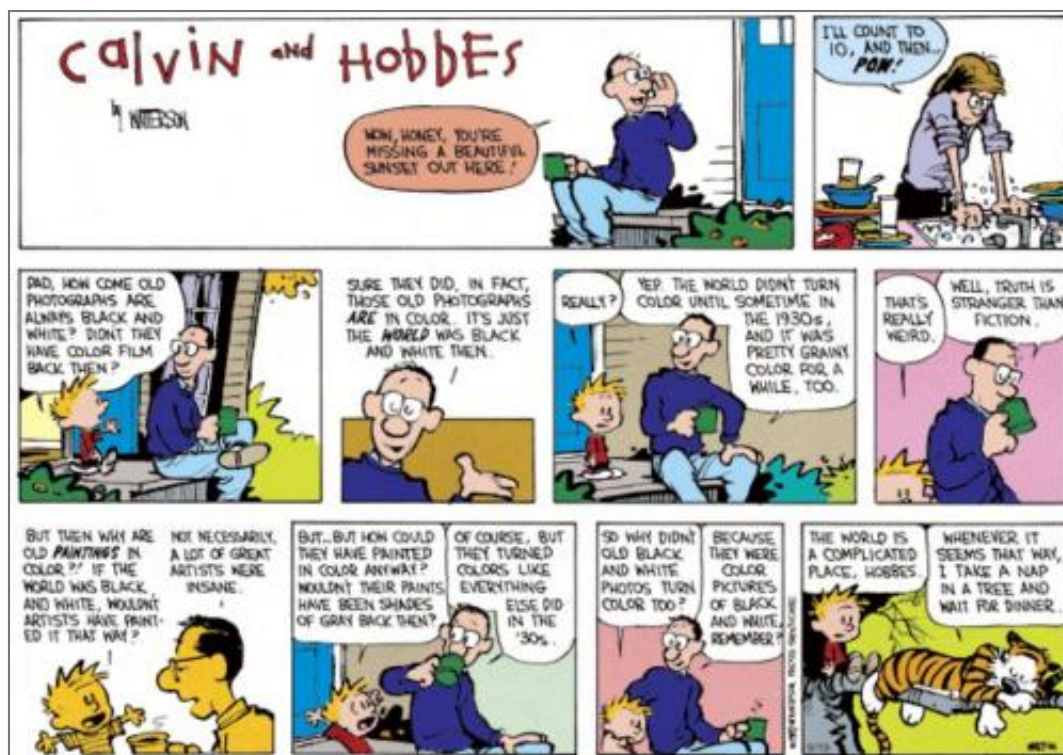
—Mary Jo Maynes, May 30, 2018

Thank you for the updates, Erik. I'm thinking of you.

—Felix Elwert, May 30, 2018

## Reworking narratives & getting into a muddle

May 30, 2018



A standard idea among historians and historical sociologists is that the "meaning" of historical events changes over time. Partially this is because events of the past get used by people in the present for political and cultural purposes. This is the wonderful domain of shifting historical memory and historical amnesia, the construction of narratives of the past to justify actions in the present. But also, there is the problem of the "meaning" of historical events and periods coming from their real consequences and not just from the lived experiences of meaning of actors within the historical moment and the present. I don't believe that the horrors of Stalinism were at all part of the motivations, visions or meanings of the Bolsheviks when they seized the opportunity created by the collapse of the Czarist regime. There were many meanings in play among the actors, and many contradictory trends and meanings within the process itself, but I don't think any of the factions envisioned the nightmare regime of the 1930s. Yet those consequences and ramifications of the revolution are part of the meaning of the Russian Revolution today. Napoleon changes the meaning of the French Revolution. And so on.

Well, I was thinking about these grand themes in the interpretation of history -- in the construction of historical narratives -- in the context of my active construction of my personal narrative of the health and medical events through which I am living. I thought: if all goes well and I am alive and well, in a few years I will look back at this period and experience its meaning in terms of all of the new insights and feelings I have acquired, the new forms of closeness to Marcia, my new appreciation of the web of loving relations in which I live. It will be constructed as an adventure with challenges, but not a period of illusory optimism, false hope, and self-deception. If I die, will that become part of the narrative, at least for some people; part of the meaning? But even if I die, the positive meanings would still be true; they wouldn't be negated by what happens, would they? And if I die, of course, then the narrative is no longer my narrative but the narrative of others about me.

I talked to Marcia about these thoughts and got twisted in the issues because of the difference between the

narrative I construct and a narrative constructed by others, and the weirdness of talking about my narrative in the face of an unsuccessful outcome. What would be my narrative if I am in hospice at some point because nothing more can be done and there were not even Hail Mary passes to be launched into the end zone? (I commented about the Vikings win over the Saints in a last play quasi-hail-Mary pass in the divisional Play-offs last year. But of course they they lost in the Conference finals to the Eagles). Would my narrative I am constructing in the present moment remain the same? My narrative has no meaning five years from now if I am dead, but the meaning of the French Revolution remains an issue far after everyone involved has died. Marcia insisted that things were simpler; I'm making things too complicated. While the story I am telling shifts as new complications emerge, the meanings I am giving the experience have deepened but not really changed and she didn't see any reason that they would. I shrugged and said something like, maybe I am too smart for my own good. She said you're not being too smart, just too cerebral. She showed me an old Calvin and Hobbes cartoon she had saved. The context was some complicated story Calvin's dad told him about how the world had changed from Black and White to color sometime in the 1930s. Calvin was totally perplexed about this and says "The world is a complicated place Hobbes." Hobbes (his stuffed tiger) replies: "Whenever it seems that way, I take a nap in a tree and wait for dinner". I added: and watch an episode of *Game of Thrones* (which continues to be a good escape from the present reality for both of us).

## Comments

That's my sister! All you need to get through Samsaric existence is The Heart Sutra and The Essential Calvin and Hobbes or Calvin and Hobbes' There is Treasure Everywhere! Or the shortened versions Om Ah Hung and that one cartoon. Deepens my breath just to think about Calvin & Hobbes.

—Janet Kahn, May 30, 2018

Dear Erik,

You and I have known each other well and for a long time--- talked often, lived together, observed accidents and recovery, heart attacks and their sequellae. And yet we keep learning. I wrote you briefly about something I learned and admired in your first response to the diagnosis of this illness. Well, your dealing with its sustained and repeated challenges, has taught me a great deal that I had not known. I will write to you tomorrow; it's after 11:00 now and time for Hobbes' solution-- a little sleep.

Love, Bob

—Robert Kahn, May 30, 2018

Here are the lyrics to "as we stumble along" from "The Drowsy Chaperone" - we find it comforting to sing it and I'm happy to do so at the drop of a phone. love, Beth

<https://www.stlyrics.com/lyrics/drowsychaperone/aswestumblealong.htm>

—Beth Wright, May 31, 2018

Nap in a tree is a good idea. I took one, on a bed, today. Almost always think clearer afterward. Or, that's my

personal narrative anyway.

—John Gastil, June 3, 2018

## Medical update

June 4, 2018

Today is the final day of seven days of outpatient chemotherapy in Milwaukee. This has pretty much absorbed every day for the past week: an hour and a half door-to-door each way + 1-4 hours at the hospital depending on whether there are labs or transfusions in addition to the chemo. The chemo infusion itself hasn't been all that demanding -- it takes about 40 minutes in total and the direct effects, so far, are mainly fatigue and mild queasiness. It's a slog, to be sure, but tolerable. And fortunately, Marcia likes to drive.

The big state-of-my-physical-being themes of the week are constipation & a spring-time post-nasal drip persistent cough which is especially troublesome at night, making it hard to fall asleep. Both are difficult to deal with. No need to get into the details, but constipation is a side effect of both the IV anti-nausea medication I take with the chemo and the cough suppressant. This seems to be a constant feature of life as a cancer patient: the medications to deal with one symptom generate side effects which then need to be dealt with. And sometimes you just have to suffer through the discomfort.

All of these symptoms interact with ever-deepening fatigue. I don't have words to really capture this well. There are lots of expressions for fatigue -- bone-weary, listless, depleted, tired, sleepy, weak, exhausted. Sometime I feel like I'm at the nadir of a ten-time-zone jet-lag where it is almost impossible to keep one's eyes open. Fatigue has now reached a point where I haven't been able to write anything on my the last chapter of my book and even answering emails and writing this blog has sometimes become difficult. I expect that in a few days some energy will return once this round of chemo ends.

The biggest silver lining of the drive every day to Milwaukee has been listening to a fantastic audiobook, Trevor Noah's *Born a Crime*. This a memoir about growing up in South Africa in the 1980s and 1990s as a mixed-race person. Noah is a brilliant writer and superb reader. I recommend this to everyone.

My energy may be depleted, but my spirits are only ruffled.

## Comments

Sending you all the positive energy I have with big, big hugs and much love!!

—Masoud Movahed, June 4, 2018

I have read born a crime and agree with your assessment . Please keep your comments coming. JJ

—John Posner, June 4, 2018

“My energy may be depleted, but my spirits are only rumped.” This sentence brought tears to my eyes and warmed my heart. Sending you all my love, -Devah

—Devah Pager, June 4, 2018

I agree. This line jumped out to me and hit me right in the heart strings. I may have to steal it for future use. Sending energy repletion thoughts and an un-rumpling of spirits!

—Josh Wright, June 4, 2018

You're not too fatigued to write brilliantly!

—Dan Hausman, June 4, 2018

So glad this particular slog is over today. Sending wellness energy whenever you or Marcia comes to mind. Jody

—Jody Whelden, June 4, 2018

Erik, you are showing an impressive and remarkable amount of courage and composure during this ordeal, and if "deserve" has anything to do with it, you will get through all of this and return to your truly unstoppable self. With all the love at our command, we wish you the best here. Martin and Mona in CA.

—Martin Goldstein, June 4, 2018

Wicky, You tell that remission dingus to be more robust! No slacking off. Its behavior so far is unacceptable!

—Andrew Levine, June 4, 2018

You rock, dear Erik! “My energy may be depleted, but my spirits are only rumped.” These are wonderful words for all. Sending vibes of support throughout this journey.

—Isabelle F., June 4, 2018

That commute sounds like a slog even if you are feeling well. I'm sure some of your energy will return once you don't have to sit in a car for several hours every day. Take it easy on yourself. Much love to you and Marcia

from friends down under.

xxx

—Janeen Baxter, June 4, 2018

Dear Erik, send you and Marcia lots of love and prayer from Yeonhee, AJ, and me. Hope to see you soon!

—Chaeyoon Lim, June 5, 2018

Your energy will return, Erik! That's a bright light to focus on.

—elliott sober, June 5, 2018

Erik, ed and I send love from Alaska and deep admiration for your courage. Also i'm So glad Born a Crime is helping pass the time. I agree it is magnificent and brilliant, especially when you hear it! Susan

—susan friedman, June 5, 2018

If I ever choose to form a Grateful Dead tribute band, thanks to you its name will be "The Rumples Spirits."

—John Gastil, June 6, 2018

Erik, Joan and I both relished Trevor Noah's book. We look forward to discussing it with you soon!  
Doug (just back from MN)

—doug maynard, June 7, 2018

## Medical Update: winding road with a pot hole we hope doesn't become a detour (short version)

June 7, 2018

To cut to the quick: I'm back in the hospital in Milwaukee, this time because of severe constipation. I will write a detailed account in a subsequent posting, but I wanted to let everyone know right away the basic story. I became severely constipated as a side effect mainly of the anti-nausea medicine. Yesterday afternoon, D. Michaelis decided that it could not be effectively managed on an out patient basis, so Marcia and I drove to Froedtert hospital and check in at 10 p.m. yesterday, June 6. Today, after a very weird enema and a couple of bowel movements followed by a diarrhea phase in the afternoon, I'm much better and definitely over the



worst. We'll probably be here for a couple of days until everything is stabilized. I'm pretty wiped out, so I won't write more now. But there are interesting details, so if I'm up to it I will write a blow-by-blow tomorrow.

## Comments

I'm impressed that you intend to spare no detail in your field reports. (-:

—John Gastil, June 9, 2018

I suffered some pretty severe constipation during my bout with cancer too, so I can relate, though I was not hospitalized over it. If this had been offered I think I might gladly have accepted it, I was so miserable...! Wishing you ease, and maybe a blood transfusion, that's what helped with my extreme fatigue. And, speaking of the narrative question, my current narrative is that my cancer was much less severe than what you are going through...

—Becca Krantz, June 9, 2018

## medical update: longer version

June 9, 2018

I don't know if anyone is really interested in all of the details of my epochal Struggle with Constipation. But I figured, writing about constipation would be a good challenge. First there is the problem of language: shit, crap, stools, poo (Australia), poop (US), turds. Then, how to make this actually interesting: Clinical details? Inner experience? Funny events?

The drama is now over: I'm back in Madison, Saturday, June 10. Fatigue, in its special form of drowsiness, has reasserted its pride of place as the Dominant Symptom. For the past week it was displaced by Constipation. This is part of the mundane reality of life as a cancer patient. The disease itself and its treatment generate a range of symptoms whose intensity vary over time: fatigue, nausea, constipation, pains of various sorts, fevers, headaches, and on and on. In recent weeks, deepening fatigue dominated my sense of well being, especially because it interfered with my finishing the final chapter of my book. Fatigue ruled. Then, beginning around June 1, constipation began demanding attention and by June 6 had knocked fatigue off its pedestal.



The story has six acts.

### **Act I. Hospitalization.**

Wednesday, June 6. Basic preoccupation of the day: dealing with a week of constipation. I live in an environment of constipating agents: nearly every medication I take lists as a side effect "constipation." Monday the 4th was the last day of my daily commutes to Milwaukee for out-patient infusions of Vidaze. Along with Vidaze I was given Zofran intravenously, a very effective anti-nausea medication. Nausea, of course, is very debilitating. Alas, Zofran causes constipation in many people. I had also taken a cough suppressant with codeine for two days to try to quell the persistent cough that has bugged me especially at night. Codeine is an opioid. Opioids are potent constipating agents. And the chemo itself is constipating.

Over the previous few days efforts at dealing with the constipation had escalated with increased doses of the anti-constipation medications and increased walking, but by June 6 it had been a week since I had a proper bowel movement and no sign that anything was improving. Then, in the late afternoon, I began having trouble peeing even when I felt the urge. I could pee, but not easily, and I definitely could not void my bladder and was beginning to feel quite a lot of bladder pain in addition to the general abdominal discomfort from the constipation. So, I called the after-hours oncology clinic number in Milwaukee and spoke with the nurse. She called Dr. Michaelis. While waiting for the return call, I went for a walk in the neighborhood. Walking is supposed to be helpful in dealing with constipation. I had already walked over a mile that day and added another half mile or so while waiting even though I was very tired. On the walk I got a call from Dr. Michaelis who felt that I should be admitted to the hospital that evening. Marcia was out shopping for baby clothes for Becky's about-to-be-born baby. She got home at 8:10. We threw things together and took off at 8:40, arriving at the hospital around 10pm. A bed was available on the same floor in CFAC where I had spent the month of April. When we arrived on the floor, we were greeted by people who knew us already, which was nice.

### **Act II. Waiting for the Enema**

The anticipated treatment for difficult constipation is an enema, but before any treatment could be done, I needed an abdominal x-ray to insure that there was no blockage or obstruction. It took until 3 a.m. to get the x-ray, and then until after 7 before it was read. There was some ambiguity, apparently, so the team decided to wait until Dr. Michaelis arrived to decide how to proceed.

While waiting I sent a selfie of my belly to Becky. My abdomen was grossly distended, filled with gas, taught as a drum. When doctors thumped on it to see what was going on, the sound was resonant. I imagined a new percussion instrument in a symphony orchestra next to the timpani. So I sent a photo to Becky who is very pregnant, one week away from giving birth. The subject line read: ersatz phantom pregnancy. She sent a photo back of her belly: "Very impressive, but I win the belly-off."

Since the symptom which precipitated my hospitalization was difficulty urinating, the doctors wanted to get that resolved quickly, perhaps with a catheter. The criteria for catheterization was whether my bladder contained

400 cl of urine after urination. I managed to pee a bit. The nurse then checked my bladder content with a portable bladder ultrasound machine that scanned my bladder and calculated how full it was. I was at 350 cl, below the threshold. I was asked if I wanted to be catheterized. I said let's wait and see how things go. In the end, this part of the problem resolved itself sufficiently that I didn't need any intervention. But for the rest of my stay in the hospital, every time I peed I had to have an ultrasound of my bladder.

Dr. Michaelis arrived around 9. The team met and went over the x-ray. She decided it was OK to go ahead with an enema.

### **Act III. Enema.**

The enema, to my surprise, was made up of molasses and milk. It was hung on the I.V. pole next to my bed. I lay on my side. A long thin blue tube was inserted into my rectum as far as it could go. "Not very far", I was informed because of the solid wall of hard (now I have to pick the right word -- let's go clinical) stool. Warm liquid flowed into the cavity. Try to hold this in for 20 minutes, the nurse told me. I tightened my sphincter. Twenty minutes? That shouldn't be too hard. I started meditating. Counting breaths. I looked at the clock. Only five minutes had passed. Felt like fifteen. Breath in, breath out. I can do this. I managed seventeen minutes, but I should have gotten out of the bed after sixteen, maybe sixteen and a half.

I didn't come close to making the to the toilet. Milky molasses gushed from me as I dashed to the bathroom adjoining the hospital bed. It looked like I was spewing (another word choice: let's go with ordinary spoken English) shit, but it was molasses: molasses on the floor, molasses on my leg, molasses on the toilet seat. The room was perfumed with the sickly sweet smell of molasses. I sat there as the remaining enema drained out, then came a wave of chunky (what word to use?) turds, little nuggets the size of strawberries. The wave stopped. I stood up to inspect the production. My butt stuck to the toilet seat because of the sticky molasses. I looked down -- not much there. A couple of dozen dark strawberry-sized islands floating in a milky brown sea. I flushed the toilet and sat back down. I passed some gas (a reasonable genteel expression). Some dribbles. Some intestinal gurgles. One more wave approached. Something was happening. I decided to add some pushing to the endeavor. Pushing and breathing. I knew I should not strain too hard, but I was desperate to get more crap out of me. This wave was painful and more prolonged. The result was only modestly more nuggets.

Exhausted, I returned to bed. The nurse and assistants came to clean up the mess.

### **Act IV. Rigors.**

After an hour or so, Marcia told me she was going to the cafe to get some lunch. I dozed off. Suddenly I woke up gripped by violent shaking and abdominal pain. Shaking all over -- like shivering uncontrollably from the cold, but magnified. I could barely manage to hit the nurse call button. "I need the nurse" I said. "What is this for?" I was asked. "I'm shaking." The nurse did not instantly come so I called Marcia. It was difficult to hold the phone still enough to even hit the right buttons. I could hardly get words out. "Come back. I'm shaking." Marcia ran back as fast as she could.

When she arrived I was surrounded by the team. She climbed into bed with me to hold me, but couldn't calm the

violent shaking. The floor doctor asked me questions, but I was shaking so much I couldn't say much. I tried to center myself with breathing, but this didn't help. For the first time in my illness I was scared. This felt like my whole system was falling apart. The shivering was much worse than the episode I had in April from the clot in my PICC line. But then, suddenly, after maybe 25 minutes, the shaking stopped. It didn't slowly taper off; it just stopped.

While this was going on the team had hooked me up to some new I.V. anti-biotics. They interpreted the shaking as "rigors" (pronounced Rye-gors) -- violent shivering that can accompany a rapid rise in temperature. This could have signaled that some bacteria had gone from my gut to my blood, perhaps from a tear or rupture triggered by the enema. That could be catastrophic. My temperature did rise slightly -- from 98.4 F to 99.1 F -- and my pulse increase to 110 beats per minute or so and my blood pressure fell. So there was reason to be concerned. But then the shaking stopped and my temperature never reached the level of a "fever." The alternative hypothesis was that this was more like shock from the abdominal pain.

The nurse took a blood draw in order to grow a culture to see if there were any bacteria. After 24 hours they would have preliminary results but it would be several days before they could know for certain. The team ordered a CT-Scan of my abdomen to be sure there was no tear or rupture. That was around 2:30.

### **Act V. Happy Diarrhea.**

2:30 to 6:30 was spent first, waiting from transport to take me to the CT-scan room, then waiting for the CT-Scan, then having the 10-minute scan, then waiting another hour for transport to take me back to the room.

In the initial period waiting for the transport I had several fairly tranquil visits to the bathroom to deposit offerings to the Gods of Intestinal Tranquility. None of these were explosive. They all gave suitable warning and just dribbled out. Liquid. No more nuggets of solid material. But with each visit to the alter, the material had more substance, harbingers of better things to come.

I was a bit worried that when the transport came I would be half way to the CT-Scan and have to use the toilet. No problem, the nurse told me. She brought me an adult "push up". I said that my two grandchildren were both using these as part of their toilet training. That didn't bother me at all. I thought it was kind of nice to be availing myself of the same means of avoiding "accidents."

The CT-Scan meant that I could not drink anything by mouth until it was over. I was getting IV fluids so dehydration wasn't a problem, but I was incredibly thirsty. All I could have was a few small ice chips. The nurse promised me an orange popsicle when I returned to the room. Still, the intense abdominal pain was gone, my distended belly was relaxing, and I felt on the mend.

When we got back to the room around 6:30, the surgery team was waiting for us. They had read the scans to see if there was any cause for concern. There were three docs, all very cheerful. Everything looks fine, they said. No tares or anything like that. My colon was quite enlarged in places because of the constipation and would take some time for things to return to normal, but there is nothing that will need surgery. As they left, the attending doc said "See you later". I declared, "I hope not." He replied, "We'll stop by tomorrow just to check

and see everything's fine." The next morning they did duck in again, felt my abdomen, and said all was well. A 30 second consult.

## Act VI. Recovery and home

I figured we would have to stay in Milwaukee a couple of more days until things stabilized, but on Friday morning Dr. Michaelis said that if the preliminary blood culture was negative, we could go home. She also went over the "big picture" scenario for the weeks ahead. Everything is still on track; nothing has been affected by the constipation episode. There is some uncertainty about when the transplant will take place, but mid to end of July or August is most likely.

In mid-afternoon the lab report came back negative. I felt fantastically better. While regular bowel movements with nice soft stools were still a prospect for the future, every trip to the toilet saw progress. So, we packed up, and headed back to Madison.

## Comments

Glad you're home and feeling better! What an arduous process.

*—elliott sober, June 9, 2018*

Whew - what an ordeal! SO glad you're feeling better!

*—Cathy Loeb, June 9, 2018*

Great story -- horrible experience.

You are a real trooper.

Best to you and Marcia.

Martin

*—Martin Goldstein, June 9, 2018*

Best story I've heard of how to deal

*—John Posner, June 10, 2018*

Best story I have heard of how to deal with obstipation. Are you taking prophylactic laxatives? JJ

*—John Posner, June 10, 2018*

Review: definitely the best-written constipation narrative I have ever read ...

—*Mary Jo Maynes, June 10, 2018*

That whole experience sounds incredibly shitty. Glad it has passed.

—*Josh Wright, June 10, 2018*

## What matters most

*June 10, 2018*

My daughter Becky gave birth this afternoon to a baby girl. Mother and daughter are, as Adriano texted, "safe and healthy and happy." My heart is full. My spirits soar unruffled.

## Comments

Joy joy, grandpa! Love from Sitka,

—*susan friedman, June 10, 2018*

Joy joy, grandpa! Love from Sitka,

—*susan friedman, June 10, 2018*

Mazel Tov!

—*Martin Goldstein, June 10, 2018*

Such fabulous news, Erik! Congratulations and happiness all around!

—*Cathy Loeb, June 10, 2018*

Hooray!!

—*Betseygail Rand, June 10, 2018*

wonderful news! Congratulations

—*elliott sober, June 10, 2018*

My heartfelt congratulations to mother, father and grandparents! What happy news!

—*Marianne Ahrne, June 10, 2018*

Congratulations!! Such wonderful news, puts everything in perspective. Sending much love.

—*Devah Pager, June 10, 2018*

Mazel tov to all of you.

—*Lew Friedland, June 10, 2018*

Congratulations to you Erik and Becky! A happy tiding indeed.

—*Mansoor moaddel, June 10, 2018*

Erik, what lovely news! Lovely! Keep those spirits up! Your many friends and fans are sending you healthy wishes every day.

—*Janet Gornick, June 10, 2018*

Good news. Congratulations

—*Lewis Leavitt, June 10, 2018*

Congratulations to everyone! We are happy to hear the news of the new arrival!

Love,

Crystal, Ben and Bradley

—*Ben Wright, June 10, 2018*

Wow!!! So happy for you all. Wonderful news.

—*jeannette golden, June 10, 2018*

Congratulations!

—*Emanuel Ubert, June 10, 2018*

What a great boost and wonderful news! Congratulations!! Sending you, Marcia, Becky, her babygirl, and the entire family much, much love!!

—Masoud Movahed, June 11, 2018

Erik, Hans and I were so moved to hear this. Amidst everything, to read your latest news -- 'what matters most' to you -- is beautiful. My syntax is garbled because my heart is full.  
Love to you, Marcia, and the entire extended family, Julia

—Julia Adams, June 11, 2018

Thrilled for Becky. And happy you're GI stuff is behind you!!!! Sending love!!!

—Kathy Cole-Kelly, June 12, 2018

## Updates Medical & Other

June 14, 2018

### **Granddaughter update:**

Becky's baby is named Ida, or to give you the whole shebang: Ida Marcia Joan Shapwright. Everyone is healthy and thriving. Ida is an enthusiastic eater and latched on to Becky instantly. Vernon seems to be very happy to have a baby sister. When told her name he said: "Ida. Hi Ida. Wake up Ida," and then he gently patted her head.

### **Medical Update:**

1. I'm now a One Symptom Guy. That's exciting. No constipation. No nausea. No cough. No abdominal pain. Just fatigue and drowsiness. And of all the symptoms on the menu, fatigue is the most benign. And the countermeasure, the easiest to do: naps.

2. I had a good consultation with Dr. Michaelis in Milwaukee today and now have a much better sense of the objectives of the current cycle of treatments. The current cycle last 28 days: 7 days of Vidaze overlapping with 21 days of Revlimid followed by 7 days off. These medicines more directly target the blasts in the bone marrow and the damaged stem cells which generate them. It has much less effect on the healthy neutrophils in my blood. When the treatment works, it can produce a substantial remission of the disease in the bone marrow. The most likely plan now is that I will have two cycles of this treatment, which will take us until the third week of July. At that point the decision-tree is basically this:

(a) If I have a complete remission after two cycles, I go directly to stem cell transplant. There would still usually be a few weeks of logistics to actually begin the transplant, and in that period I would start a new cycle of treatment to avoid a treatment hiatus, but that cycle could be interrupted when the stem cell transplant is ready.

(b) If I have a partial remission, I go to a phase III clinical trial called IOMAB that has been shown to be very effective for people in precisely my situation. As in all phase III trials, I get randomly assigned to the treatment group or to a control group (called in this case the "salvage" group).

(c) If I am in the treatment group, I get the IOMAB treatment and then go to stem cell transplant; if I'm in the control group, I repeat a full third cycle of Vidaze+Revlimid.

(d) If after the third cycle, I have a complete remission, I go directly to stem cell transplant; if I have a partial remission, then then go to the IOMAB treatment and transplant just as in (c). This would mean a transplant around the end of August.

So, the timeline is a bit stretched out from what I initially thought in April, but according to D. Michaelis, all of the indications are still that this is on track.

## Comments

Greetings to Ida!!

And thanks for this detailed update and revised plan. It's good to hear your 'voice' again!

—Mary Jo Maynes, June 14, 2018

Welcome to Ida. And hooray for one symptom! Naps are the absolute best!

—Josh Wright, June 14, 2018

This sounds positive. I wish things would work out smoothly.

—Lefeng Lin, June 14, 2018

A very warm welcome to Ida!!! And a big hooray to the eradication of symptoms and things being on track: wonderful news! Here is hope that fatigue is also gone very soon -



Much love!!

—*Masoud Movahed, June 15, 2018*

Thrilled about Ida!!!! Sounds like a clear plan. I vote for option 'a' but they all sound promising for sure. Think of you often Eriki! Xo

—*Kathy Cole-Kelly, June 15, 2018*

Wellcome Ida! Thinking of you Erik, send you positive vibes and thoughts. And YES TO NAPS!!

—*Rodolfo Elbert, June 15, 2018*

## Mini-mini update

*June 16, 2018*

Yesterday morning I went to the UW hospital cancer center for a transfusion. I have had these every week or so -- a bit more frequently when I was in the hospital -- when my hemoglobin level fell below a certain threshold. To my surprise, I was given two units for the first time. I can tell you unequivocally: two units are way better than one. One unit takes the edge off of my energy depletion. It means I won't get out of breath climbing stairs. Two units has given me some semblance of actual energy to do things. Maybe this will also restore sufficient mental energy to return to my chapter. This weekend is filled with visitors (Jenny and Safira are back for a few days, and my brother Woody and his wife are all visiting); I'll give it a try on Monday.

## Comments

Glad your energy is up, Erik!

—*elliott sober, June 16, 2018*

Gland to hear from you Erik, happy to hear about your rising energy level, and I hoping the best for you.

—*Mansoor moaddel, June 16, 2018*

Glad to hear that thi

—John Posner, June 16, 2018

Glad to hear that things ar

—John Posner, June 16, 2018

Looking up. Please keep us up to dat

—John Posner, June 16, 2018

Date. JJ

—John Posner, June 16, 2018

Dear Erik, I've been following along and am sending so much love your way. Congratulations on the new addition to your family. Love to the whole Wright clan!

—Amelie Davidson, June 16, 2018

Great news, Erik! Seeing family is in and of itself energizing! Sending you all much energy and love!

—Masoud Movahed, June 17, 2018

Great news, Erik! Seeing family is in and of itself energizing! Sending you all much energy and love!

—Masoud Movahed, June 17, 2018

## More on drowsiness and fatigue (if I can keep my eyes open)

June 20, 2018

It is a cool, wet, gloomy day. I'm sitting in the recliner in my living room. I was lying on the couch, but I knew there was no way I could write anything unless I moved to the chair. I slept over 10 hours last night (with five night-sweats time-to-change t-shirt interruptions), and woke up at 8 feeling pretty rested and even a little energetic. Maybe after breakfast I could sit down and do some writing on my chapter. That hope lasted about an hour. Then the drowsiness returned, eyes closing unless I consciously, with effort, keep them open.

Today is Wednesday, June 20. Last Friday I had a double transfusion of red blood cells at the UW hospital. I

went in expecting a single unit, but they said that there were two units on the order. This was the first time I had gotten two units at once. I have been more or less getting one unit whenever my hemoglobin count falls below 8. Those extra red blood cells took the edge off the fatigue, but I never experienced the transfusions as a massive qualitative leap on the fatigue spectrum. After the transfusions last Friday, I definitely felt better, but still, the improvement was not dramatic -- from completely wiped out to mildly droopy.

Saturday and Sunday were an entirely different story. I woke up Saturday morning feeling fully rested and ready for action. I'm usually the first up in the household. Marcia is a night owl. This weekend, Jenny and Safira were visiting from Colorado, and both were sleeping in as well. I went downstairs. Made my breakfast (an omelet), emptied the dishwasher and cleaned up the kitchen, organized our Tupperware cabinet by putting all of the tops on the bottoms (this had been a chaotic mess for quite some time), chopped up a watermelon into bite-size chunks for easy consumption, and made a chicken salad from the previous night's left-over dinner of finely chopped celery, sweet onions, and sweet peppers. And I wasn't tired at all after all that. It felt so good to be taking care of tasks which would otherwise fall mainly on Marcia. Two units of red blood cells pushed me across some magical threshold. This made for a wonderful weekend with my granddaughter. We could actually play together a bit in the back yard. My brother Woody and his wife Beth were also visiting (staying at a hotel close to where my mother lives), and so I was able to connect much more fully with them.

I definitely had enough energy physical and mental to work on my writing, but I didn't want to take time out from being with family members, so I put this off until after they left.

Everyone was gone by Monday morning. I had a blood draw on Monday which confirmed a much improved hemoglobin count, from 7.5 on Friday to 9.0. When I got home, I took a rest, and then read through what I had written on the final chapter to get the narrative back firmly in my mind. I took a rough 1 mile walk as part of my exercise regimen. It was a hot day and I felt the need for another nap when I got home. And so the day slipped away. By Tuesday morning I had slipped back across the magical threshold -- depleted, nodding off, little energy for anything. I still manage the walks -- I can force my body to do that -- and have short conversations. And watch a few world cup matches. But that's about it.

So, a two unit transfusion did make a wonderful difference for 2-3 days. I will ask my doctors if it is possible to have this more frequently, so that I get a little more respite from the drowsiness. But perhaps there are good medical reasons to avoid so many transfusions. I am told that there are small risks with transfusions even with the very clean blood supply we have these days, and since I probably will be needing these for quite some time, perhaps this is part of the calculation about how much I should get.

Tomorrow I go to Milwaukee for another bone marrow biopsy, and then back again on Tuesday the 26th, after the refined results are available for a stock-taking consultation with Dr. Michaelis.

## Comments

Hi Eriki,

So glad you had all this energy for the visits! I'm sure it was wonderful to see Jenny and Safira and all. 2-year-

olds especially require a lot of energy (and watermelon).

Love,  
MJ

—*Mary Jo Maynes, June 20, 2018*

Oh eriki, this is a journey eh? I hope your Milwaukee visit goes well, the biopsy isn't too painful and you're celebrating Jenny's birthday today. Happy birthday Jenny! Xoxo, kathy

—*Kathy Cole-Kelly, June 20, 2018*

So happy to hear that you had such a great time on weekend with family being around - Much love!

—*Masoud Movahed, June 20, 2018*

## Update

*June 21, 2018*

Marcia and I drove to Milwaukee this afternoon for a bone marrow biopsy to check on how well the current treatment regime of Vidaza+Revlimid is doing in subduing the mutant hematopoietic stem cells. On Tuesday we'll return to find out the results and get more clarity on the next phase of treatment.

The biopsy was the best ever. The discomfort level was certainly not worse than going to a dentist where you get Novocain and then a filling. I listened to Janet's guided meditation on pain reduction on the drive in (if you missed this I describe it in the April 30th posting). Then, once I was on the procedure bed and the team began the prep work, I rehearsed the images and narrative more informally: thanking my pain receptors for all of the wonderful work they've done for 71 years, but asking them to back off today, and then visualizing my bones as a porous, vibrating matrix of molecules with lots of open space which could loosen up and allow the extraction needle to slip in. I started slow, deep breathing, in through the nose out through the mouth, directing all of my attention to the area on my sacrum where they were working. I didn't even notice when the actual extraction occurred, which was the acutely painful moment during my first biopsy. I only knew that had happened because I was told "We're done".

I discussed the biopsy with the physicians assistant afterwards. She said that my experience was at one end of the spectrum. Some people say it isn't painful at all; others say it is the worst pain in their entire life. She also said that my body was so relaxed that it made her job much easier. I wonder if that also contributed to why this was so pain free this time -- she didn't have to work as hard and this contributed to the ease of the procedure as

experienced by my very cooperative pain receptors.

I also told the PA that on Friday I had gotten two units of blood to raise my hemoglobin level and that as a result I had been filled with energy on the weekend. I asked why I wasn't given two units more often since it made such a big difference. She explained that there were long term risks involved, especially since it is uncertain how many transfusions I will ultimately need. Every time I get a transfusion I also get iron in my blood. The body has no good way of getting rid of iron, so the more transfusions I would get, the more iron would accumulate. This excess gets stored in various parts of the body and can cause real problems. In fact, at the end of the transplant process, a year or so from now if all goes well, I will probably have to have what was a very popular medical treatment in the 18th century: blood-letting. This is called these days phlebotomy ( "phlebotomy" is not to be confused with "lobotomy"). The basic idea is to remove blood so that when the now healthy a vigorous hematopoietic stem cells make new red blood cells those cells will absorb the stored up iron, thus gradually getting rid of my excess supply. This all makes sense and certainly makes me less eager to get the extra units of blood. But it sure was nice last weekend.

## Comments

Love your descriptions of the guided imagery and relaxation techniques. So glad Janet gave you those!!!! Hope the weekend is a good and easy one. Xo

—Kathy Cole-Kelly, June 21, 2018

Yes, iron over load is a risk but since it can be easily treated by phlebotomy the risk is small. Please give my best to Woody and Colleen. Please keep Betsy and I up to date. JJ

—John Posner, June 21, 2018

Many thanks for the update. Your description is superb and relaxation techniques well worthy of emulation. I wish you well.

—Mansoor moaddel, June 21, 2018

Thanks for the update. Very interesting stuff about pain management. By the by, I got to read your essay on the four strains of anti-capitalism. Well done! Very persuasive.

—John Gastil, June 22, 2018

## A new Anti-Drowsy Strategy

*June 22, 2018*

Today I adopted a new anti-drowsiness strategy. Mind you, I am on the fourth day of a chemo holiday having taken my last dose of lenalidomide (Revlimid) on Monday night, and drowsiness was a listed side-effect of the pills. But still, I have a new strategy and we'll see if it works later. But, on a first trial today, it worked fantastically.

Up until today, after breakfast I settled down in the living room, either on the couch or the recliner, more or less for the day. This would be broken up by occasional visitors and walks. But mostly I would be in a kind of liminal state between being fully asleep and fully awake -- nodding off, watching a bit of TV (world cup, Netflix), listening to music or a podcast, dozing, reading a bit, answering email, working on a blog post, drifting off. Today I decided to try something different. After breakfast I went back to the second floor of the house and decided that this should be my base of operation. I would come downstairs for meals, walks and visitors, but mostly I would spend my time either in my study or in bed. I would try to take proper naps, with real sleep, whenever I felt my eyes grew heavy and drowsiness was taking over; otherwise I would be fully up and seeing if I could write or read.

Right after breakfast at 8:00 I took a nap. That, I think, may have been the first time in my adult life that I took a real nap immediately after breakfast. I felt deeply asleep and woke up at 9:30 refreshed. I thought maybe I could get something done. Two tasks: working on my last chapter and doing a little bit of preparatory work for the video presentation of my paper for the ASA (one of my project assistants and advisees, Pete Ramand, was coming over in the afternoon for this). I worked intensively for an hour and a half, and then remembered that the Iceland/Nigeria World Cup match was on, so I tuned into that until Iceland was down 2-0 and it was clear it was going to lose. Then I worked another hour on the chapter and stopped at 1 for some lunch. I emailed Pete to come over around 3, and went to sleep for a second nap at 1:30. I was woken by the doorbell at 3:30 from a deep sleep.

I groggily went downstairs and let Pete in (Marcia is in Philly meeting Ida) and explained that I had been asleep but that it was fine to be woken up. We went to the kitchen for coffee and began to chat -- about how I was, about what lay ahead, about Pete's dissertation ideas. That lead into a fantastic, intense, intellectually interesting discussion of three topics Pete has been thinking about. He is at a critical juncture that the best students often face: they have a number of really terrific ideas both in terms of the importance of topics and their specific, creative theoretical insights about the salient issues, but they feel stuck on how to proceed. Pete didn't want to abandon any of these themes, but clearly he could not do a full blown dissertation that dealt with all of them. Maybe he could opt for what these days is called a "three paper dissertation" -- three publishable smaller projects rather than a single over-arching monographic dissertation. But Pete knew that I disliked that approach to dissertation research, at least for most of the substantive issues that my students work on. I much prefer a single integrated dissertation with a strong narrative arc, depth of analysis, and (of course) exciting punch line.

So we talked. He explained each theme. I reflected on what I saw as exciting in what he had sketched out and

the different ways he might move forward with each idea. We discussed practical research possibilities, and the role of good theoretical essays that would map out each theme. Suddenly it was 5:30. We decided to postpone the video project until Monday, and instead went for my daily 1 mile walk.

I know Pete found my advice and feedback helpful. But for me, our conversation this afternoon was a fantastic gift: to be lost in intensively working through interesting and important ideas with a student who is serious, insightful, and fully committed. I learned a lot in our two-hour exchange -- about left and right versions of nationalism in Europe and the tricky problem of inclusionary versus exclusionary nationalism; about populism and anti-populism; about new party formations and their confusing social bases in youth and other categories. This is one of my great pleasures in working intensively with PhD students as they gradually move from mentees to younger colleagues -- how much I learn from our interactions. But also, right now, finding the intellectual energy to be lost in this kind of conversation was exhilarating.

So, maybe this is mostly a nice feature of my chemo holiday, but maybe my strategy helped as well. In any case, I'm now going to fully embrace proper daytime sleeping rather than drifting-in-and-out naps. Once again, Hobbs' advice to Calvin was spot on (see May 30 posting).

## Medical Update

*June 26, 2018*

Marcia and I went to Milwaukee for a consultation over the detailed pathology results from the **June 21** bone marrow biopsy. Once again, the results indicate that I do not have a robust remission: the concentration of blasts in the bone marrow was 17%. A complete remission is <1% and minimal presence is 1-5%. The upshot: My AML is now officially called "refractory." Refractory means stubborn or unmanageable. Stubborn imputes motives to my miserable damaged hematopoietic stem cells, so I guess it is better to simply say the AML is unmanageable.

The next opening for the Iomab-B clinical trial is probably July 9, and Dr. Michaelis would like me to enter the trial then. To do so I would still need to pass a number of screening tests to be sure that my kidneys, liver, heart and probably some other things are functioning well. Dr. Michaelis does not think this will be a problem. Assuming that this timeline works out, this means that I would enter the clinical trial on July 9 or shortly thereafter. To avoid there being any deterioration of my underlying disease process between now and then, I will begin a new cycle of Vidaza+Revlimid on Thursday, June 28 in Madison.

I have been reading about the IOMAB-B treatment on line. The sentence I especially like is: "In a Phase 2 clinical study in 58 patients with advanced AML or high-risk myelodysplastic syndrome (MDS) age 50 and older, Iomab-B produced complete remissions in 100% of patients and these patients experienced transplant engraftment at day 28." The mechanism through which this works is pretty interesting. The infusion is of a monoclonal antibody called BC8 that has been somehow labeled with a

radioactive isotope, iodine-131. This antibody targets an antigen called CD45. This antigen is expressed by white blood cells and hematopoietic stem cells. The radioactive antibody BC8 therefore diffuses throughout my body seeking out any cell that expresses CD45. That's what antibodies do: they look for the specific antigens that they dislike. And when they glom onto the antigen, BC8 deftly delivers a lethal radioactive particle into the cell. Zap. This is like the more familiar radiation therapy that is targeted at a tumor, but instead is delivered to individual cells. The research center that has developed this technique is quite fond on militaristic metaphors. They refer to the delivery device on the radioactive monoclonal antibody as a "warhead enabling technology platform." They also call this general strategy ARC: "Antibody Radio-Conjugates that combine the targeting ability of monoclonal antibodies with the cell killing ability of radioisotopes." Apparently this achieves a higher level of myeloablation (wiping out the bone marrow) with little toxicity to other tissue than is possible with the existing chemotherapy methods. That sounds good to me.

Here then is the basic scenario as I understand it now:

1. On July 9, I sign the consent forms and take the screening tests (or take them shortly after the 9th).
2. If I get randomized into the "salvage group" (i.e. the control group) then I get the treatment I would have gotten in the absence of the clinical trial. This would be a third attempt, using some other chemo, at producing a robust remission. That would probably be in the hospital for a month. If it worked -- which seems unlikely -- I would then go directly to BMT (Bone Marrow Transplant, which really means bone marrow stem cell transplant). If I am still refractory, I go to the clinical trial Iomab-B treatment.
3. The Iomab-B treatment. Once the donor stem cells have been secured (which may take a few weeks -- donors take vacations), a date is set for the actual transplant. That is called Day Zero. In the Iomab-B treatment there are 14 days of treatment before this, which can only begin once Day Zero is firmly set. There a variety of steps -- various days to test my sensitivity to iodine-131, days of treatment doses of the monoclonal antibody BC8, beginning anti-rejection medication, etc. But after those 14 days, I am properly conditioned for the transplant. If I get into the treatment group and there is no special delay in getting the donor stem cells, then I think this means the transplant would occur late July or early August. If I don't get into the treatment group, then this would be delayed a month.

So, that's how things stand at the moment.

## Comments

I enjoy seeing your scholarly mind at work on the medical issues. Recalcitrance seems somehow a fitting style descriptor for you, however unfortunate in this particular case. Hope your body decides to cooperate with what sounds like really first rate medical care, provided with non-patronizing information.

—Myra Ferree, June 27, 2018



## a video

*June 27, 2018*

Two days ago my graduate student Pete Ramand came over to do some video recording. The main task was to record a presentation I was slated to give on a panel at the American Sociological Association meetings in August. Since I can't physically be at the meeting, I thought a video presentation would be a good substitute.

So, we set up an improvised videography studio in my study. After we were done, I asked Pete to do one more recording, of a song I made up for my grand kids. The song is to the tune of "Camptown Races." I first began concocting it in February Of 2016 when I spent a week or so with Becky, Adriano and Vernon when Vern was 3 months old. I had spent six weeks in Australia the previous summer to get to know Jenny and Mark's baby, Safira and February was my chance for an extended time with Vern. One evening I was tending the baby so Becky and Adriano could go out. He was being fussy, so I was marching around the house soothing him, and began making up the song. It began "I got two grandbabies, both a delight / doo-dah, doo-dah / Safira Decker and Vernon Shapwright / Oh doo-day day / Safira she lives down under, in Sydney Aus-trail-i-aye / while Vernon he lives in America in West Philly, P.A." Over the next year or so I added and modified verses, but the song remained geared to two grandchildren. Whenever I saw the kids, and often when I would skype or facetime with them, I would sing our song, so it has become something special between us.

And then Ida arrived. I knew right away when Becky got pregnant that I would have to modify the first verse to include the new baby, but until we had a name it was kind of hard to figure it out. I made a few attempts, but I couldn't squeeze her in without breaking what Becky told me was the scansion of the song. Becky quickly came up with the solution: "Got three grandchildren all a delight doo-dah, doo-dah / Safira Decker, Vern and Ida Shapwright / Oh Doo-dah day/ Safira was born down under, in Sydney, Aus-trail-i-aye / while Vern and Ida both were born in West Philly, P.A."

I wanted to make a recording of the song now, before the stem cell transplant, so the kids would have it. I'm not feeling morbid about this, just connected to them. I thought it would be nice to share it with all of you, so I have attached it here.

## Comments

Lovely song and a beautiful voice. I wish you well Erik.

*—Mansoor moaddel, June 27, 2018*

Beautiful Erik!! thanks for sharing. All the best wishes, Erik, we are thinking of you.

—Judith Leavitt, June 27, 2018

Oh eriki, this is classic you. Love it!!!

—Kathy Cole-Kelly, June 27, 2018

Oh eriki, this is classic you. Love it!!!

—Kathy Cole-Kelly, June 27, 2018

Great song! Lucky grandchildren.

—jeannette golden, June 27, 2018

Perfect. What lucky grandkids!

—Cathy Loeb, June 27, 2018

Lovely song, Eriki!

—Mary Jo Maynes, June 27, 2018

"Your grandpa's name is Eriky, he likes to study sociology" --- love, love, love, so much love!!

—Masoud Movahed, June 27, 2018

The best rendition ever!!

—Susan Davidson, June 27, 2018

Eriki have you read emperor of maladies? Tom thinks you would really like. Xo

—Kathy Cole-Kelly, June 29, 2018

Esma loved the song!

—Loren Peabody, June 30, 2018

This is lovely.

—Pamela Oliver, June 30, 2018

Lovely! I wish nothing but the best for you.

—Keedon Kwon, July 9, 2018

## Annoying glitches

June 30, 2018

Friday, June 28: I'm sitting a chemotherapy bay in the UW Carbone Cancer Center waiting for the second day's infusion of seven-days of Vidaza. The actual infusion takes about half an hour, but there are always various kinds of initial prep work to be done and the chemical concoction for this specific chemo is not made up until the patient is in the chemo room. So if everything is glitch-free, the whole process should be take 1-2 hours. For today, alas, glitches piled up. Nothing dire, but annoying:

- The story starts yesterday, day-1 of cycle two of my Vidaza+Revlimid combo. Because I was anemic -- my hemoglobin count turned out to be 7.2 -- I also received two units of red blood cells. In the prep for all of that, I first had to have labs. The routine is that before drawing any blood, a nurse flushes the PICC line with saline. I have two PICC ports, one with a purple bit on the valve, the other with a white bit. The white one worked OK, but was sluggish. The nurse couldn't flush the purple one at all, no matter how hard she pushed on the plunger. No problem, I was told: We can use the functioning port today and then fix the other one tomorrow **when you come in for your infusion**, by forcing Alteplase (a potent drug for treating blood clots during heart attacks) into the PICC line in order dissolve any dried blood which might clog the line).
- Next step yesterday: The Vidaza infusion. The nurse took my temperature just before the infusion, 98.7F. Immediately after, it was 99.8F. Over the next two hours it fluctuated between 99.8 and 100.4. That higher number is the one that triggers concern by the doctors. Then came the two units of red blood cells, basically a two-hour process. About an hour into that I felt some queasiness -- not quite nausea -- followed by a violent, painful spasm akin to retching, except there was no bile and nothing came up. It was more like the spasm of a bad cough. Two more episodes like that occurred before I was done. When we left my temp was down a bit, 99.7.
- Back home my temperature drifted upwards, crossing 100.4 again in the late afternoon. My coughing also increased -- not with the intensity of the episodes at the clinic, but persistent, dry bronchial coughs, just like during the first cycle of this chemo. I called the Milwaukee clinic, spoke to the triage nurse, who then spoke with the PA on Dr. Michaelis' team. Since I didn't have any chills and didn't have other symptoms, they said to just watch things.
- The night was miserable because of coughing. At 3 a.m. I took the cough medicine that sort of worked the last time around. I don't know why I didn't do this right away, but I didn't. By 4 or so a.m. I was

asleep, only waking for the usual change of t-shirts because of night sweats and sleeping until almost 10. Marcia checked my temperature periodically during the night; it kept drifting upward, at one point reaching 101.6 F. I didn't want to call the Madison clinic because they might say I should go to the E.R, and I felt the temp was unlikely to reflect an infection, and I didn't see the point of calling the Milwaukee clinic. When I awoke at 10, my temp was still elevated.

- Today: 10:15. I first called Milwaukee and then Dr. William's office at the Madison Hematology Oncology Clinic. They wanted me to come in as quickly as possible to get lab work done before the chemo infusion, which was scheduled at noon at the Infusion Center in the hospital, a different place from the Oncology clinic chemotherapy center. They would shift the chemo back to the usual oncology clinic. Dr. Williams also wanted a chest x-ray because of the cough. So, off we went.
- 11:00, in the lab. Today the nurse couldn't get either port to work. She tried hard, but couldn't get a blood return from yesterday's functioning port and had no luck getting the other one to work. So I had to have the blood draw from a conventional poke, the first since April. She then tried to get the Alteplase sent to the oncology clinic lab. While that was pending I went off for the x-ray. When I came back, still no Alteplase. It ended up taking over an hour to get the drug. The computer system seemed to have balked at moving a drug from one part of the hospital where it had been authorized to another. The problem, it seems, was that each part of the hospital has its own pharmacists and pharmacy, and so such move requires multiple people to sign off on it. Once we had the Alteplase we had to wait another hour for the drug to dissolve the obstruction in the PICC line. It worked.
- Finally we could get on with the Vidaza infusion. Only, it too had been ordered for the infusion center. Another delay in getting the order shifted to the oncology clinic pharmacy.

Later: By the time everything was done and the last drip of Vidaza dripped, it was getting on towards 5:00. I wasn't irritated really at anyone and don't think it is right to chalk this up to "hospital bureaucracy." They have protocols in order to avoid errors, and inevitably that will slow things down. But, still, it was frustrating to squander the day after a double transfusion where my energy level was back up.

## Comments

Bleg. I am sorry to hear about the cough misery and the PICC line woes. You are in our thoughts and I appreciate the regular updates.

—Pamela Oliver, June 30, 2018

## A Glitchless Day

*June 30, 2018*

Appointment at UW hospital infusion center at 10:00a.m. Arrived a few minutes before. Checked in. Shown to the chemo cubicle. Various bits of prep work: vital signs (all good); flush the two PICC lines with saline (worked perfectly); get me a warm blanket. The Vidaza has to be made up fresh after the recipient arrives. It arrives at 11:00. The usual double-check with two nurses reading all of the labels and codes and confirming that I am indeed Wright 2-9-47. Vidaza starts to drip at 11:15. Done at 11:45. Twelve minutes of saline flush. Done by noon. Glitchless.

## Comments

Let's hear it for glitchless days! :)

xo

*—Cathy Loeb, June 30, 2018*

Fantastic news! May the glitchless days continue for ever - much love!

*—Masoud Movahed, June 30, 2018*

Hi Erik! Sending love. My parents are in Brooklyn visiting and you came up several times in our conversations today. I am keeping up on your blog and am sending so much love to you Marcia, Jenny, Becky and their families! ??

*—Amelie Davidson, June 30, 2018*

Yay for days without glitches!!!!

*—Kathy Cole-Kelly, June 30, 2018*

Glitchless, at last! Those plugged tubes were very upsetting.

*—Magali Larson, July 1, 2018*

## Another new understanding: "loss of appetite"

*June 30, 2018*

I have never really understood the full meaning of "loss of appetite." I know that in the assisted living facility where my mother lives, loss of appetite can be a problem and residents can lose weight in unhealthy ways. In my head I just thought, "Just eat! You know its good for you." After all, you don't have to be hungry to eat. So, just eat because you know you should.

Well, now I know that loss of appetite isn't the same as not feeling hungry, or at least the simple equation of the two doesn't work. I am finding that I now feel real aversion to most foods. Many sweet foods taste disgustingly hyper-sugary sweet. I love glorious, perfect, watermelons. Marcia cut one up into nice bite size chunks. After three or four I just could not comfortably eat more. Same with cantaloupe. Salty food often taste too salty. At the long glitch-filled day at the oncology clinic I asked Marci to get a variety of kinds of potato chips which I never **normally** eat. We hadn't come prepared for a all-day event, so she did a trip to the snack shop. I couldn't eat more than a chip or two from each: too salty, too greasy. I was hungry -- not ravenously hungry, but hungry. But it would have required more conscious effort than I was prepared to exert to override the taste aversion. I'm finding it pretty hard to find something that I feel I actually want to eat. Smoothies with yoghurt and strawberries and almost no sugar goes down pretty well. Cheerios with milk still tastes good. Marcia's Mom's red Lentil soup, which I have always loved, initially tasted really good tonight, but after eating half a bowl, I had to consciously make myself eat the rest. It's not that I was full; its that the soup became much less appealing, bordering on unpleasant. **My taste buds are clearly dazed and confused.**

So, now I see why eating enough can be a challenge -- for the elderly, for cancer patients, for people with other conditions. So far I've been able to avoid losing more than a few pounds, but it has become a bit harder recently.

I don't recommend acute myeloid leukemia as a weight-loss strategy.

### Comments

I am very sorry to hear about the loss of apatite, Erik - but please make sure that you eat enough. Perhaps, a good strategy is to eat more of the foods that are still appealing to you.

*—Masoud Movahed, July 1, 2018*

I am also sorry to hear this as I know you have always really enjoyed different foods during the many meals we have shared. At this point, I would probably go for calories over content if that works!

Much love,  
Susan

—Susan Davidson, July 3, 2018

Erik, you might try something hyper-bland. Now Foods makes a Pea Protein powder that I mix in milk, which is like drinking liquid chalk dust (I have some, if you want me to drop it off). Also, maybe: unseasoned tofu, baked potatoes, and brown rice. As far as maintaining sufficient calories to avoid weight loss, you might consider mixing shots of walnut oil in milk. You can obtain the caloric density of a small meal in just a handful of gulps.

—Adam Szetela, July 4, 2018

## How to register on the Bone Marrow Stem Cell Donor Registry

July 3, 2018

If you are between 18 and 40 I urge you to register on the International Bone Marrow Stem Cell Donor Registry. (If you're over 40 your stem cells, alas, are less agile, so except in special cases you're not eligible). There are currently around 27 million names on the registry. Three of them had Human Leukocyte Antigen (HLA) markers that were perfect matches with my own. Without a perfect match, my chances of survival would be much lower. One of these donors is now completely confirmed. This stranger will help save my life.

To register, you sign up on the [Bethematch.org website](https://bethematch.org). They will then send you a kit for you to take cheek swabs which you send back to the Registry. That's it. Your DNA goes into a database, and then when someone needs a donor, an attempt at matching the patient's DNA with someone on the list is made. You could save someone's life.

## Comments

I don't tend to wish I were younger, but for this, I would!

—Cathy Loeb, July 3, 2018

So grateful for this perfect match donor. How beautiful is humanity when it acts in solidarity!

—Isabelle F., July 3, 2018

I have passed this age, but will urge the younger ones in the family to register. Many thanks for this Erik.

—Mansoor moaddel, July 3, 2018

Going to recommend this trip all the med students!!! Tom did it long time ago!

—Kathy Cole-Kelly, July 3, 2018

Eriki. Can you send me this as a text so I can copy and paste it? Thx!!!! Kathy

—Kathy Cole-Kelly, July 3, 2018

Along with registering to vote, I make this extra credit for my students every semester!

—Adam Szetela, July 4, 2018

## Medical update

July 5, 2018

We met with our hematology oncologist today. On Monday, the 9th we'll meet with the head of the stem cell transplant team, so I will get fine grained details about that procedure and the clinical trial then. But here is what I know for sure:

1. My last dose of Revlimid is on July 18th. This will be followed by a week without any chemo. I will then have a bone marrow biopsy on July 25th.
2. If I have a robust remission -- which I think means blasts at <5% -- then I would go directly to the non-clinical trial transplant process. This would mean the actual transplant would most likely occur mid-August.
3. If the remission is not robust, then I will enter the clinical trial for Iomab-B, assuming that I continue to meet all of the eligibility criteria.
4. If I am randomized into the treatment group, then the transplant would occur mid-August.



5. If I am randomized into the "salvage group" I will undergo another cycle of chem in the attempt to create a robust remission. This is basically what would have happened if there had been no clinical trial available. Dr. Michaelis proposes a chemo regimen called CLAG-M, which includes the chemicals Cladribine, Cytarabine, and Mitoxantrone. This is a more potent (and toxic, alas) brew than anything I have had so far and would be done in-patient in Milwaukee. This treatment would last a month.

6. If after the CLAG-M treatment I have a robust remission, I go to transplant. This would put the transplant into September.

7. If I do not have a robust remission after the CLAG-M chemo, then I would go into the treatment group in the Iomab-B clinical trial, also leading to a transplant sometime in September.

So, what seems clear is that I will be in Madison for the rest of July, and then be in Froedtert Hospital starting sometime in August.

In terms of how I'm feeling right now, the only really persistent issue is fatigue. Much of this is connected to low hemoglobin. I had a two-unit transfusion on Tuesday because my hemoglobin level was 7.1 (the normal range is 13.6-17.2). That boosted my energy on Wednesday, but today the level was back down to 7.2, and so tomorrow morning I will get another two units, and perhaps platelets as well. The chemo, I was told today, both affects stem cell production of red blood cells and probably directly depletes red blood cells already in my peripheral blood. So, I will probably be getting more regular transfusions in the weeks ahead. Fortunately tomorrow, my transfusion appointment is scheduled for 8:30 and the world cup match between France and Uruguay starts at 9.

## Comments

I wish I could pray. I think of you.

—Magali Larson, July 5, 2018

Focusing on the robust remission obviously, but grateful to know there is a clear path forward in any case. Your fighting spirit elevates us all. Sending continuous energy and peace of mind.

—Isabelle F., July 6, 2018

Glad the World Cup was scheduled to help get you through this challenging time. Encouraging path forward in your series of matches.

—Myra Ferree, July 6, 2018

Hi Erik, sending you good vibes and thoughts from Argentina. Did you choose a world cup team already? I think Uruguay has a strong cooperative movement, and you were a rock star in your visit there. You should root for them!

—Rodolfo Elbert, July 6, 2018

You will defeat this challenge, dear Erik, just like how you defeated other challenges. Sending you a big hug and much love!

—Masoud Movahed, July 6, 2018

## Exuberant vigor

July 6, 2018

Monday, July 2: last day of Vidaza.

Tuesday, July 3: I woke up completely depleted. I went for labs. Hemoglobin, 7.1. I was given two units of red blood cells. This didn't make a dramatic difference, but it did take the edge of the fatigue.

Wednesday, July 4: Slept most of the day.

Thursday, July 5: More labs in Milwaukee. Hemoglobin at 7.2. Didn't feel quite as listless as on Tuesday, but still pretty wiped out. They ordered transfusions for Madison for Friday.

Friday, July 6: Double transfusion in the morning. Watched France beat Uruguay in the World Cup. My student Rodolfo commented on my blog from yesterday: "I think Uruguay has a strong cooperative movement, and you were a rock star in your visit there. You should root for them!" I tried to, but my heart was still with France. By 12:30 we were headed home. And, to my surprise and delight I was filled with energy. Not just a marginal improvement -- a fantastic surge of vigor. Today was a glorious July day, a perfect July day -- low humidity, mild temperature, cloudless sunny sky. And I felt a vitality in tune with the day. I went home, had some lunch, worked for a couple of hours and made real progress on my chapter. Allen Hunter came by at 3:00 and we went for a long walk to the Lake Wingra wetlands boardwalk. Then, back home for a nice goodbye conversation with my student Ayca Zayim who is about to move to Massachusetts to begin a job as an assistant professor at Mount Holyoke. Not a moment out of breath, just a feeling of being fully in the world enjoying the physical

activity, the beautiful day, the good company and good conversation. And when everyone had left, I put in another hour writing. And still I am not tired.

I know this won't last, but what a joy it is to feel in good health if only for an afternoon. That is what I am tasting right now: fully vigorous, no symptoms, nothing but being alive and at ease in my body. If this lasts the weekend, perhaps I'll finish my book.

## Comments

What a lovely, vigorous and connected day, Erik - so glad to read this. And happy that the summer weather collaborated. Love, Julia

*—Julia Adams, July 6, 2018*

Great news, Erik! I hope the weekend is good.

*—elliott sober, July 6, 2018*

Wonderful! Glad you had a really good day.

*—Debra Satz, July 6, 2018*

Good to read that you felt better today.

*—Mansoor moaddel, July 6, 2018*

Wonderful; a vicarious joy.

*—Dan Hausman, July 6, 2018*

What a delight to read. Sending much love!

*—Amelie Davidson, July 6, 2018*

What a great description of euphoria!!!!

*—Kathy Cole-Kelly, July 6, 2018*

So nice to hear this, Eriki! And greetings from Frankfurt am Oder. I'm here for a conference, right on the border. We walked across the bridge to Poland last night for dinner. I meet Ron and some longtime friends in France tomorrow.?? to you and Marcia.

---

—Mary Jo Maynes, July 6, 2018

Hurrah! Such a much needed reprieve. And how wonderfully you used it.!

—Myra Ferree, July 7, 2018

Go go go!!!

—Isabelle F., July 7, 2018

## Update while being transfused in Milwaukee

July 9, 2018

I'm peacefully lying on a trans/infusion bed in Froedtert Hospital in Milwaukee getting a unit of platelets and two units of red blood cells. My platelet count had crashed to a dangerously low level, and they didn't want me to drive back to Madison without the infusion. Since my hemoglobin had once again dipped below the transfusion threshold (this time to 6.9) it seemed best to do everything here today. That basically means 5 hours or so of infusions. So it goes.

Earlier in the morning we had an informational consultation with Dr. Hari, the head of the transplant team, to discuss what lies ahead. He basically confirmed the scenarios laid out by Dr. Michael's last week: After the biopsy on the 25th there are four scenarios:

- (1) direct to transplant if I have a robust remission: transplant mid-late August.
- (2) If not, into the clinical trial and the treatment group: transplant mid-late August;
- (3) If not randomized into the treatment group, then in the salvage group, in which case I get another round of trying to get a robust remission: in-patient chemo in August with the CLAG-M chemo brew. If robust remission, go to transplant: probably sometime in late September
- (4) If I don't get robust remission, into clinical trial Iomab-B treatment: transplant probably early October.

I did learn two new technical things about my condition and treatment. First, the two mutations I have -- Translocation 3;4 (or something like that) and 5q deletion -- are on different stem cell clones, rather than two mutations on all of the damaged stem cells. Dr. Hari liked the metaphor of Big Cats: some of my mutated stem cells are tigers; others, lions. All of them are ferocious. It seems that the first cycle of Vidaza+revlimid managed to get rid of all blasts in the bone marrow with 5qDel, so the 17% blast number was entirely of the other type. The other thing I learned is that if I do get the Iomab-B treatment, I will have to spend three days in a lead-lined room because I will be radioactive. The treatment delivers radioactive iodine-131 directly to the AML cells and

stem cells and kills them. That will make me radioactive for three days. Marcia can visit me for short periods then, but not stay with me.

## Comments

As always, I admire your analytical rigor. I wish you well Erik and many thanks for the update.

—*Mansoor moaddel, July 9, 2018*

Sending you big hugs and much love, Erik!

—*Masoud Movahed, July 9, 2018*

thanks for the update Erik. Never wrote here, perhaps better than email

Wish you all the strength you need to get over this one.

Paradoxically yesterday in class I learned

all I want to know about translocations and its various incarnations

Morale: a big cat is a big cat, some are more easily tamed than others, but they are all tamable .

—*alberto palloni, July 10, 2018*

## A posting that has nothing to do with Leukemia

*July 10, 2018*



On Sunday our neighbor knocked on our door to tell us that a tree had split in half and fallen on our garage. We hadn't heard a thing. It wasn't a windy day, just a pleasant light breeze. But sure enough, a substantial part of the large hackberry tree in our backyard had split off from the trunk and landed on the garage. Today there is a crew in the backyard removing the tree, a major undertaking. Apparently there was no real damage to the garage, originally a carriage barn built in 1904. "Must be a sturdy structure," commented the arborist.

## Comments

Berkeley wondered whether a tree falls if nobody hears it. But then he didn't consider the noise of the removal. Perhaps this a pivotal moment in epistemology.

—*Dan Hausman, July 10, 2018*

Our last pear tree fell on Midsummer's Eve, unheard by all, including the neighbors who were closer to it. Luckily it fell in our garden, not theirs. Our youngest grandchild, Makida, 9 on Sunday, made a tragic face and sighed when she heard about it: "You don't know how much I had been looking forward to eating those pears". The fact is that she never cared much for pears but she doesn't miss an opportunity to be dramatic.

—*Marianne Ahrne, July 10, 2018*

!!!

One if our old cottonwoods split during a storm years ago and fell on our neighbor's power line while she was away. Not good for the stuff in her fridge but damage wasn't too bad.

—Mary Jo Maynes, July 11, 2018

Or perhaps a metaphor -- the branch is leukemia and the sturdy structure is Erik?

—Elizabeth Thomson, July 12, 2018

## Fatigue emotions, writing

July 10, 2018

This past weekend I would describe as a disquieting interplay of energy levels and emotional intensity.

On Friday I was euphoric with physical vitality after the double transfusion in the morning. I slept well that evening. Saturday morning I felt rested and ready for an active day. My two nephews came over to watch the England-Sweden world cup match with me. Great fun.

After that, I went to my study to work on my book. I was in a somewhat tricky part of the chapter, writing about the problem of the complex terrain of identities which political movements confront in attempting mobilize people into a collective political actor. The specific bit of text concerned those identities which are obstacles for progressive politics rather than constituent elements of progressive politics. I was writing about "exclusionary nationalism", an awkward term to avoid having "national identity" as such being the issue. My efforts at clarifying this were getting too complicated. I was adding too much about alternative views, about the debates over the rise of right-wing populism, and so on. This is typical of my way of sorting out a problem when I write: I add too much complexity, then I cut it out and put the excised bit into a file called "cuts in progress for chapter X", and try to distill a simpler exposition.

By 2:30 or so I was well into the adding-too-much-complexity phase and realized it. So I cut the material, and looked at the screen and tried to start over. Usually at this point what I do is reread the lead-in to the knotty passage -- the few paragraphs or sometimes pages just before it -- and then mull over possibilities. That is a point where I need maximum mental focus: keeping the overall structure of the text actively in mind + the immediate passages before the issue at hand + the alternative ways of approaching the immediate exposition. I like this moment -- it can be intellectually interesting to sort all this out. But of course, it sometimes takes several iterations and requires lots of mental energy.

When I tried to summon up the energy I hit a wall. The closest analogy I can think of is "bonking" for athletes



when suddenly they are utterly depleted and cannot summon any physical energy to carry on. I bonked mentally. And then, immediately, I was hit by a wave of emotional bleakness. I was so disappointed -- I had felt so good the day before and still felt good, positive energy to work on my book today. I had hoped for a weekend of vitality, but it was gone. I knew there was no going forward right then and felt emotionally overwhelmed. the only thing to do was to get into bed and sleep. Maybe that would help. I went from my study to the bedroom. It was dark -- all of the blinds closed -- and crawled into bed, under the sheets. And I burst into tears, sobbing.

I am a person who cries pretty easily in moments of emotional intensity, but this is almost always in moments of happiness, positive fullness of feelings. I tear up in sentimental romantic comedies on long airline flights. The evening of the day I was invested as the ASA President and got on a table at the Wisconsin Department Party at the ASA meeting to say something to my colleagues, students and former students gathered together, I choked up. And in my present circumstances, there have been many times tears have been triggered when I talk about my grandchildren or get some moving letter or email from a friend or former student, especially when I am trying to read it out loud. Last night I tried to read aloud to Marcia a wonderful letter from dear French friends, I could only get through half a sentence before she took over. Over the past months, I have also had moments when I cried as feelings of sadness surface, but these have always been when I am with Marcia, usually at night in bed when she can hold on to me and comfort me (especially stroking my head). Those are moments of release where my tears are embedded in my deepest sense of connection and love. The tears bring relief and ease.

But on Saturday, I lay alone in my bed crying with feelings of dark despair. (Marcia was out to see the documentary movie about Mr. Rogers). I didn't feel relief, just suffering and loneliness, disconnection -- I was alone facing this, my life crumbling, hope an illusion. I don't think I exactly cried myself to sleep, but after fifteen minutes or so I was asleep and slept for two and a half hours.

When I awoke, the bleakness had passed. I had a memory of feeling despair without feeling despair. I felt rested and, if not exactly energetic, certainly able to get up and do things. I went back to the computer, looked over the text and cuts, mucked about with things for a hour or so, not making much headway but not feeling blocked either. Then I called it quits for the day.

Saturday night as I was falling asleep I reviewed in my mind the issues that needed resolving in the text. I often do this: reread a day's writing just before bed, rehearse it as I fall asleep, and dream about solutions. At around 3 am I woke up for a t-shirt change (night sweats continue) and knew what I wanted to say and how to say it. I almost went to the study to write it down, but I decided the thoughts were crisp enough that I didn't need to.

Sunday morning after coffee I got back to work, wrote for a couple of hours and resolved the knotty issue to my satisfaction. I felt my physical energy waning in the course of the day, but not the mental fatigue from the day before.

## Comments

Glad you are hanging in; I know it's hard. Sending healing thoughts.



—Debra Satz, July 10, 2018

This is real stuff, Erik. Thanks for writing this and your other blog posts, which I have been reading. One thing that is interesting is the way that your illness has highlighted the writing process and the ways intellectual insight intertwine with emotional highs and lows.

Decided to put the rest of my comment into an email.

—Pamela Oliver, July 10, 2018

Sounds like you are experiencing a rollercoaster of emotions - no doubt all quite natural. I am sorry to hear that you felt alone. That's probably quite a natural feeling. Sending lots of love, affection and "we're with you on this journey" thoughts.

xxx

—Janeen Baxter, July 11, 2018

Wow. Thanks for sharing your experience. Flag to know I'm not the only cryer out there. I, too, went to the Mr Rogers film; felt a tear thirty seconds in and was in the edge of full crying almost the whole film.

Sorry for your feelings of despair, and I hope writing about all this helps keep it all in perspective.

(And on a work note: I'll remind the editor to send me anything with your name on it, so I can proofread it for you.)

—John Gastil, July 11, 2018

Thanks for sharing. It can't be easy to be this open about the highs and lows. In addition to rooting for you, I am rooting for the book which is taking on its own personality as you reveal how you are wrestling with it. Your writing process sounds so familiar, including letting your subconscious do some of the work of getting you through the tricky parts.

—Myra Ferree, July 11, 2018

Erik, as always, your courage, and clarity -- and the fact that you somehow manage to combine those things -- just amaze me.

Sending love and hugs, Julia

—Julia Adams, July 11, 2018

Oh eriki, exquisite description of wrenching feelings. So natural and normal but so wish you didn't have to experience these tough ones. Thinking of you often. Hoping the crispness of mind and clarity of feelings are

dominating your days. Xoxi

—Kathy Cole-Kelly, July 11, 2018

Wow, indeed!

This is quite a story, Erik. I'm glad things were clarified for you. Emotional intensity is sometimes so hard to figure. For me the mind-body connection around emotions is so apparent, and can still be hard to figure out, or do anything about.

I had one additional thought - the irony of your having watched the World Cup while trying to analyze "exclusive nationalism" - and connections there?? (not with your emotional state, but with the analytic problem you were grappling with)

—Mary Jo Maynes, July 12, 2018

PS - as I write this I am sitting in a garden in Paimpol, France, where we are spending a few days with French friends and bemoaning intense nationalisms and our equally evil heads of state, while also having a lovely time walking and looking at flowers and the sea.

—Mary Jo Maynes, July 12, 2018

## Fever roller coaster

July 14, 2018

### Tuesday, July 10

This was the opening day of the workshop in the Real Utopias Project on democratizing finance that I had been planning for well over a year. Fifteen people from around the world were gathered here to discuss the papers they had written in response to the anchor essays for the conference written by Fred Block and Bob Hockett. I of course could not attend, but I skyped into the opening session to greet people and had planned to do the same at the end of the conference on Thursday to discuss the concrete plans for the book that will come out of the project. The skype went fine -- I was focused and filled with good cheer and energy.

I then worked for a while, making satisfying progress, until the world cup match between France and Belgium. I was torn over which team to root for: I have strong sentimental ties to France, but Belgium was the plucky underdog. The overdog won.

After the game, I took a nap, then had a lovely visit with John Roemer. John and I have known each other for almost 40 years as members of the NBS(M)G: the Non-Bullshit (Marxism) Group. Marxism is now in parentheses since most of the members of the annual meeting no longer think of themselves or their work as capital-M Marxist. We went for a long walk around the Vilas Park pond and talked intensely about our children and the conference. By the time he left I was tired, but had no inkling that something was brewing.

### **Wednesday, July 11**

Restless night. Woke up pretty tired and just not feeling right. So I took my temperature just to check. It was 100.2 F, just below the threshold (100.4) when I am supposed to call the Cancer Clinic. By 10 a.m. the threshold was crossed: 100.8 F. We kept taking it every five or ten minutes for the next hour or so. It rose to 101.2 and the hovered just below or above 101. So, I called the Milwaukee clinic, the triage nurse consulted with my hematology team, and called back. I should immediately call the cancer clinic in Madison to find out where I should go. They didn't want me to drive to Milwaukee because they want a neutropenic fever treated within an hour of its identification. I called the hematology oncology clinic and was told to come to the UW hospitals ER. That made me a bit anxious because of all of the infections that might be lurking there. As it turned out, the ER was very calm and well organized. They were expecting us and quickly ushered us into room rather than just a cubicle. I got hooked up to an IV machine and anti-biotics while preparation for a bed in the cancer ward were being made. I was even able to watch the second half of the England-Croatia game.

By mid afternoon I was in my room. Labs were taken. I was severely neutropenic and my hemoglobin count had dropped to 6.1. No wonder I felt so depleted -- that is the lowest it has been. This was pretty discouraging since I had just gotten two units of blood on Monday.

The night was dreadful: I started coughing sometime in the late afternoon, the same kind of dry, upper respiratory cough that plagued me during the Vidaza phase of this treatment cycle. The cough medicines that had calmed things down didn't do much good. My fever continued above 101 throughout the night. At 4 a.m. I was given some Tylenol, which dropped the fever and made me more comfortable.

### **Thursday, July 12**

I was exhausted in the morning. When the senior fellow and his team came in for rounds I could barely understand what they were saying. When they mentioned certain medications I was taking, the names seemed unfamiliar. I was in a confused, foggy, mental state. That passed pretty quickly, but another disquieting moment.

I cancelled the plans to skype into conference this morning, but still wanted to see Tom Malleson and Isabelle Ferreras, since I wanted to discuss the plans for the next Real Utopias Project conference on Democratizing the Corporation to be held sometime in 2019. They have taken over my role as coordinator of the conference. They came by at 9:30. It was good to see them, but I was barely able to talk because of coughing; words did not come easily. Bob Hockett came by for a short visit at around noon, and then Fred for a longer visit to talk about the next steps in the process of turning the conference papers into a book.

My fever stayed below 100.4 after the Tylenol wore off, so that meant that the 48-hours-with-no-fever clock started ticking.

The rest of the day was spent mostly in bed. I got snatches of sleep, but the coughing continued pretty much unabated. In the late afternoon Marcia and I went for a walk, with me tethered to the IV pole and wearing a super-tight, snug fitting neutropenic mask. The layout of the ward here is not as congenial for a stroll -- conventional straight hallways rather than connected rectangles forming a figure eight -- but in any case I got very tired quickly so we were only out of my room for ten minutes.

At around 9 pm, after watching a couple of episodes of GLOW (Glamorous Ladies of Wrestling) on Netflix, I started earnestly sucking menthol cough drops. That in conjunction with the two cough medicines I was taking seemed to quiet things down just enough to fall asleep.

I woke up at 3 a.m. extremely hungry. Marcia had brought a supply of various things she thought I might find palatable. I tried the oatmeal. It was too sweet, but I forced myself it eat it. I found if I took a spoonful and wolfed it down followed by swig of milk I could get through the bowl.

### **Friday, July 13**

My fever remained below the critical threshold. My blood counts showed a modest rise in neutrophils that put me into the moderate risk rather than the high risk category, so the attending physician said that I could be discharged (I almost wrote, "we could be discharged" since Marcia is always by my side) at the end of the afternoon so long as my temperature stayed down during the day. This created a certain drama whenever a nurse came in to take my vitals. The readings were all in the 99s, occasional upper 98s. One becomes incredibly tuned into all sorts of numbers as a cancer patient.

In due course, we had our "discharge papers" filled out with all of the instructions for what we should do: new pills to take; some old ones to discontinue. We stopped by the pharmacy on the

way out and headed home.

Strawberry smoothie with added whey protein for dinner, then some phone calls, and the final three episodes of GLOW and to bed, pretty late for me around midnight. Marcia, of course, stayed up a bit longer to clean up.

## Saturday, July 14

Last night was dreadful because of the coughing. Our strategy of increasing the dosage of the two cough medicines didn't do much. But I had one interesting experience in which for a fairly extended period of time I was more or less drifting back and forth between being awake a sleeping while continually coughing, the coughs becoming part of dreams. So I know I got more sleep than I thought. I'll describe this in a later post.

Now it is around noon. I had a helpful phone consultation to clarify the dosages of cough medication and their timing, and for the size of the dosage increase. The coughing has subsided for the moment. My red blood cells are doing their job, so on the sheer energy front I'm much better. The nutritionist at the hospital also made a terrific suggestion on the food aversion front: Citrus, because of its acidity, can mute taste buds, so combining citrus with foods I would normally like might make them more palatable. This morning I had scrambled eggs. After two bites, the aversion threshold had been crossed, so I drank a gulp of orange juice and then had no problem with the next forkful of eggs. Alternating orange juice and eggs got me through full plate. Maybe this will work with other things.

So, things have settled down a bit.

## Comments

You excel at writing and bringing your community into the loop with you through your ups and downs. I am glad to be following from Brooklyn. Sending much love to you, Marcia, Jenny, Becky and their families!

—Amelie Davidson, July 14, 2018

I really appreciate these journal entries, Erik. I'm not really sure why, but they are always the first emails I open. I regret having missed what I'm sure was a good conference. I did read the papers, but my plate had piled up, so I decided at the last moment not to make the trip.

I'm delighted to see that Tom Malleson has gotten involved. I was an outside reader for his dissertation. We've stayed in touch ever since. A smart young guy with high energy.

Keep on truckin', comrade.

—David Schweickart, July 14, 2018

I am very sorry that the last few days were so rough as you had fever, but glad to hear that it dropped and the coughing subsided. Wishing wholeheartedly that your apatite for food is also back very soon. Sending you a big, big hug! Love -

—Masoud Movahed, July 14, 2018

## mini-update to last post

*July 14, 2018*

After the last post I took a two-hour nap and really slept. At one point I started to cough and Marcia suggested I suck on a cough drop. I did and fell instantly back to sleep. Now I'm up, no coughing, and feeling even a little perky, drinking the remnants of this morning's smoothie.

## Comments

Hi Erik,

Thank you for your writings about work, play, rest, fever, crying, and esp the love and closeness between you and Marcia. I'm so glad that your fever has subsided. I'm also grateful for your teaching us about the details of your illness and treatments, and their complexities. I wish this were a class and not your experience.

Big hugs to you and Marcia,

Joan and Kjell

—Joan Fujimura, July 16, 2018

## Limnal states

*July 17, 2018*

In my post of July 14 I briefly mentioned that for an "extended period of time I was more or less drifting back and forth between being awake and sleeping while continually coughing, the coughs becoming part of dreams." The vividness of that experience has faded a bit. Like everyone -- I suppose -- I have from time to time had dreams in which at some point I wasn't sure if I was awake or sleeping, occasionally having dreams-within-dreams in which I would awake from the internal dream and still be dreaming, which can be very confusing. This was different.

Mostly when I have had these episodes of persistent coughs, the coughing would stop when I actually fell asleep. That was the key purpose of the cough suppressant -- to interrupt the coughing sufficiently to let me fall asleep, during which time the cough would remain dormant. But this night the coughs just wouldn't stop: four or five in a row, then a brief pause, perhaps for as long as a few minutes; then four or five more coughs in a row again; and on and on. The coughs varied in intensity, but not in their persistence. And yet it seems, at one point I was dreaming and thus must have been sleeping; but this night, the coughing continued even then. Each bout of coughing would shake the landscape, sometimes like an earthquake, sometimes like a fade-in/fade-out in a film changing the scene entirely. My vantage point was sometimes in the landscape, sometimes floating above it, but always being jangled by it. I would drift in and out of this dream-state, to get up to pee, to drink some water. I don't think I was every 100% awake, but I'm not sure. And always there were the coughs.

Well, that is all over now. The next day the doctor who was supervising my stay said I could triple the dose of the dextromethorphan (non-codeine cough suppressant) and double the dose of teslan perls (a cough suppressant small capsule), alternating them every 3-4 hours. That seems to have done the trick. No more coughing. I may not need them any more, but for the next couple of days I will keep taking them at night.

## Comments

I know the last few days have been really rough, dear Erik, but am very glad to hear that the coughing has come to a halt. Big hugs and much love!

—Masoud Movahed, July 17, 2018

## Medical update

*July 17, 2018*

Yesterday, Monday the 16th, I had a blood draw and consultation. My hemoglobin remained well above the transfusion threshold, so it seems that my red blood cells like it when they don't face the depredations of revlimid. In the consultation, however, I was told that one of the PICC-line blood cultures they had take on July 11 when I was admitted to the hospital had grown a bacterium associated with a PICC-line infection, and so my PICC-line had to come out. I had grown quite fond of my PICC-line, since it spared me the annoyance of getting poked whenever I needed blood tests, transfusions or infusions of various sorts. But it had to come out. It was a simple, painless procedure. Putting the thing in required being under an x-ray monitor so the technicians could thread the plastic line properly through a vein in my arm and into my chest. But pulling it out was just a matter of, well, pulling it out.

Since release from the hospital I have been fine. Still 5-8 t-shirts a night from night-sweats, which of course disrupts sleep a bit. But with naps I am managing to feel pretty rested. No temperature; no coughs; no nausea; no constipation. My taste buds remain stupid, but the strategy of cleansing the palate with OJ after every bite of a food that isn't completely aversive seems to work pretty well. Marcia's Geek yogurt strawberry smoothies with added whey protein remain reliably delicious. And to top things off, I have made significant progress in my chapter, definitely heading towards the end. So, I'm in a nice period of ease.

## Comments

Wishing this period of ease lingers! All the good thoughts!

*—Josh Wright, July 17, 2018*

Magnificent

*—Sarah Siskind, July 17, 2018*

You're amazing eriki. So glad for a peaceful and productive phase. Xoxoxo

*—Kathy Cole-Kelly, July 17, 2018*

Fantastic news! Sending you positive energy with a big hug!

*—Masoud Movahed, July 17, 2018*

Eriki - I've been thinking of you since our quick visit. Reading today that you are feeling in a phase of ease is a wonderful thing. I love you and Marcia.



—Jennifer Wilgocki, July 17, 2018

Relieved to know that you are more at ease now, from home, and can get some rest. Sending tons of good energy to you and Marcia!

—Isabelle F., July 18, 2018

Glad you're feeling better, Erik, and that your chapter is progressing!

—elliott sober, July 18, 2018

It is encouraging to read your latest (cautiously) upbeat report, Erik. Your blog is inspirational. Norty

—Norty Wheeler, July 18, 2018

## A public appearance

July 20, 2018

Since early April the closest thing to a public appearance for me was skyping into the Democratizing Finance conference. Today I ventured forth to the studios of Wisconsin Public Radio for an interview on socialism for the program To The Best of Our Knowledge. It was exhilarating. During the interview, my fatigue fell away and I felt fully engaged, explaining complex ideas, talking about democracy -- understood as democratizing power relations over the economy -- as the core principle behind socialism, moving from one theme to another with ease. It was such a pleasure to talk about these things in a public setting.

Afterwards, as expected, I was tired. And now I can barely keep my eyes open so it is time for my afternoon rejuvenating nap.

## Comments

Wonderful!!!

—Susan Davidson, July 20, 2018

Hooray!!

—Mary Jo Maynes, July 20, 2018

Glad the radio show went well. I'm sure you aced it.

—elliott sober, July 20, 2018

This is fantastic news, dear Erik!

—Masoud Movahed, July 20, 2018

## Mini-medical update

*July 20, 2018*

Yesterday I had a blood draw and consultation. This was the first lab without my friendly PICC line, which had been removed on Monday. As a follow up to the positive blood culture the lead to the PICC line removal, I needed blood draws from each arm, thus two pokes. Two nurses worked on me simultaneously, one at each arm. They didn't exactly time their pokes perfectly, but it was pretty close. I don't actually mind shots or conventional blood tests very much, but it definitely was less pleasant than the PICC line. I assume at some point I will get a new one.

The results: my hemoglobin was actually up from Monday, indicating that now that I am not getting any new chemo, the healthy part of my bone marrow is producing red blood cells. White blood cells, platelets and neutrophils are also moving up for the same reason. So, I didn't need a transfusion. All good.

I feel I am now entering a period, perhaps for only a week or so, of medical calm. I'm on chemo holiday. I am pretty much without symptoms aside from fatigue and scrambled taste buds. For the fatigue, good naps are really making a difference, so I do have a few hours every day where I can work. Finishing my book is in sight. And for the confused taste buds, the strategy of palate-cleansing with something acidic like orange juice after every bite seems to enable me to eat a wider variety of food.

On Wednesday night my student Masoud brought over a tray filled with his fantastic spicy Iranian chicken kebabs. I had had this dish before my taste buds went kablooie, and it really is wonderful. Everyone in our household loves it (Judy and Bob had had it on a previous occasion). Marcia told Masoud that she wanted the recipe, but when he described it as involving a fairly complex marinade for ten hours followed by outside grilling with a little fan doing something or other, I think we'll rely on him for future kebabs. When Masoud had called the day before proposing the kebabs, I told him that probably I wouldn't be able to eat it this time around

because of my unhappy taste buds. He said he would make them anyway. I told him that would be lovely since my cousin Wally and his wife Nancy were visiting us from New York and this would be our dinner even if I had to eat something else. As predicted, I ate a bite, which tasted fine; but then with the second bite, I was clearly at the food aversion threshold. So I drank a gulp of OJ. The next bite was fine. I then drenched the kebabs with pain yogurt, another kind of acidic counterpoint. Now I could eat several bites before the OJ chaser. Kebabs and orange juice is not, I imagine, a traditional Iranian combination, but it managed to tame my disoriented taste buds.

## Comments

I'm guessing you may already know about this book, but if not it might be helpful with the taste buds challenges. It's called "the cancer fighting kitchen." It's a cookbook, but also has quite a bit written about the taste buds. I found it really useful and there are a number of dishes that I continue to make from this book.

—Annabel Ipsen, July 20, 2018

Sounds yummy!

—Kathy Cole-Kelly, July 20, 2018

## I finished the chapter, and thus the book

July 24, 2018

I just finished the final chapter of the book on which I have been working, *How to be an Anti-Capitalist for the 21st Century*. The relief is enormous. The final chapter is probably not as well-honed as the others since it hasn't gone through the process of public presentations, dialogue, and written feedback. But as my 100 year-old mother says when I ask her how she's feeling, I think it's "good enough".

Here are the final three paragraphs which wrap up the overall argument of the book:

In the developed capitalist democracies today there is a widespread sense that the political-economic system is not working well, perhaps even unraveling. Both the state and economy seem incapable of responding coherently and creatively to the challenges we face: adaptation to the ramifications of climate change, let alone mitigation of its underlying causes; the global refugee crisis, which is likely to intensify in coming decades as climate refugees are added to war refugees and economic migrants; the increasing economic polarization within

wealthy countries; the prospect of either a “jobless” future caused by long-term effects of automation and artificial intelligence, or at least a future in which market-generated jobs are either well-paid jobs demanding very high levels of education and knowledge, or badly paid, precarious jobs. Capitalism, as it exists in the world today, is a major obstacle to effectively dealing with all of these issues.

One reaction to these trends is gloom and doom. Capitalism seems unassailable. The disarray, and in some places the disintegration, of traditional political parties, has generated a sense of political incompetence and paralysis. This has created the opening for right-wing, nativist populism. One can easily imagine a future in which the erosion of liberal democracy accelerates and slides into much more authoritarian, if still nominally democratic, forms of government. Such developments are already apparent in some capitalist democracies on the periphery of Western Europe. This could certainly happen as well in what had been thought to be the most stable liberal democracies.

But this is not the only possibility. Capitalism as it exists in the world today need not be our future. Popular disaffection with capitalism is widespread even in the absence of confidence in the viability of a systemic alternative. Resilient efforts at escaping the depredations of corporate capitalism by building new ways of organizing our economic life can be found everywhere. And there are serious efforts at creating new political formations, sometimes within traditional parties on the left, sometimes in the form of new parties. The potential for constructing a broad social base for a new era of progressive politics exists. The contingencies of historical events and creative agency of activists and collective actors will determine whether this potential is realized.

## Comments

Wow! Congratulations on finishing this and thanks for posting this section of the chapter. I'm really impressed that you could keep the focus necessary despite the fatigue, emotional ups and downs, etc. This reminds me that I also want to thank you for something else. I am also working on the last chapter of that book that's taken much too long. The chapter is on young women's rebellions in the Age of Revolutions in Europe. When we were hiking in Wisconsin in February you gave me some good advice about how to re/define "political" in order to include young women's rebellions. I wrote it at the top of the chapter draft for inspiration, and it has really helped. And I'm getting close :-)

—*Mary Jo Maynes, July 24, 2018*

Bravo!

—*Dan Hausman, July 24, 2018*

Congratulations on finishing the book! Those last 3 paragraphs are great!

—*elliott sober, July 24, 2018*

Congratulations on finishing the book! Those last 3 paragraphs are great!

—*elliott sober, July 24, 2018*

Do you really think that a generation or two ago (i.e. within our lifetimes) that there was all that much more confidence in the viability of a systemic alternative? We may have talked as if there were, even to ourselves, but did anybody really believe it – except in bad faith? The difference now is not that there is reason to think that systemic alternatives are more or less viable than they used to be. It is that the Left has gone missing. How that happened is a long and complicated story – certainly, the demise of (big-C) Communism had a lot to do with it, even if nobody cared much any more for the Soviet Union or (formerly Red) China. But it was not the only factor, by any means. If I understand what you're up to, you think that the way to get to a better place is through "real utopias" (by which I think you mean feasible institutional arrangements that defy the logic of capital accumulation in one way or another and perhaps even implement a socialist value or two – solidarity, maybe, or (as Oscar Wilde put it) a penchant for endless meetings. More likely, I suspect, we will get back to where we ought to be in ways that cannot now be envisioned, but that could develop unexpectedly and suddenly – a kind of return of the repressed. To that end, it may not be helpful to join the consensus view according to which more or less traditional understandings of socialism are kaput. It could be more helpful, and also theoretically and politically sounder to reconstruct and build upon the Old Time convictions – perhaps not so much on their merits (viewed out of particular contexts) but on a sense of the ways they address the real and on-going discontents of life in capitalist societies.

—*Andrew Levine, July 24, 2018*

Well done, Erik !!!

—*Hillel Steiner, July 24, 2018*

Congratulations, Erik! A heroic achievement under such difficult circumstances. Big hugs.

—*Cathy Loeb, July 24, 2018*

Congratulations, Erik, what an enormous accomplishment! & the paragraphs are great.  
I love that final sentence -- the analysis & sentiments behind it. May that potential be realized.  
xox Julia

—*Julia Adams, July 24, 2018*

You are an inspiration, Erik.

To be clear, you don't inspire me to get cancer. Rather, you inspire me to write more eloquently (and more often), regardless of my health. But I think you knew that... (-:

—*John Gastil, July 24, 2018*

Great news, Erik!

—*Vivek Chibber, July 24, 2018*

Eriki - I'm so happy for you - your relief is palpable! Congratulations!!!

—*Jennifer Wilgocki, July 24, 2018*

This is wonderful to hear!!! Well done!!!! Now, Enjoy the much deserved rest :-)

—*Isabelle F., July 24, 2018*

Congratulations!

—*Emanuel Ubert, July 24, 2018*

The (W)right book at the right time ;-) Can't wait to read it.

—*Sarah Kaiksow, July 25, 2018*

This is wonderful news!! Congratulations, dear Erik!

—*Masoud Movahed, July 26, 2018*

## Mini-updates

*July 26, 2018*

1. I sent the book manuscript to the Verso editors today. I told them I might still tinker a bit and make some tweaks between now and the stem cell transplant, but I thought they should see the whole manuscript while there was still some chance for me to make small changes. And then, after I sent it off, I thought some of you might want to dip into it as well since I've been talking about it since April. So, I posted it on my [website](#) . Here is the direct link to the book: **Draft book manuscript, [How to be an Anticapitalist for the 21st Century](#)**.

2. Yesterday was my bone marrow biopsy in Milwaukee. The physician's assistant who did the procedure asked if I cared whether she did it on the left or right side. I said I had no preference. She said, well, since we've done many more on the right side, left's do the left. It turns out there is some difference in the underlying architecture of the left side of my sacrum which made for a less simple drilling. Next time I'll express a preference. I did my usual meditation. It worked pretty well, but not as well as last time. I still invoked the image, while doing slow, deep breathing, of walking down a narrow path through a jungle with tall dense greenery on each side. (Actually: the greenery was more like formal high groomed hedges in a fancy British garden). Like last time, I could hear tigers and other beasts rustling about behind the hedges with occasional growls, but this time during my walk on one or two occasions a paw swiped out from the hedge with claws extended. I was only barely grazed once, half way through, then everything quieted down for the rest of the walk. (This was actually the visualization that was part of my mediation during the procedure; the paws were unexpected). "We're done", I was told. The results will be available Friday or Saturday (July 28 or 29), and I will get a call to discuss what's next at that time.

3. My hemoglobin was down again. Not as low as some times, but still low, and it was certainly the case that I was feeling once again dragging fatigue. So this morning I got two units of very enthusiastic red cells, and this afternoon and now into the evening I feel totally energized, once again the feeling of deeply at ease in my body without having to think about it. Often, probably most often, the transfusions just reduce the fatigue, but I have now also had several striking cycles of depletion followed by real vitality. The shifts back and forth not only bring into relief the past taken-for-grantedness of my body. I am not just more aware of the difference; I experience the absence of fatigue differently. I've used the expression "at ease in my body." Maybe that captures part of what I'm feeling. But there is also almost a cellular joy in diffused in my physical state, not just in my emotions: body happiness maybe. It won't last, I know. But I'm content for now.

## Comments

May the cellular joy and vitality last forever, dear Erik! Very much looking forward to reading the final version of the book!

—Masoud Movahed, July 27, 2018

Congratulations. I read the introduction and it seems like you must be feeling satisfied to have been able to complete this before you head into this next month and the healing this Fall. Thanks for sharing it with us all. I have been enjoying reading it so much. It's clarity and analysis are so beautifully done. Jody

—Jody Whelden, July 27, 2018

Erik, Congratulations on finishing the book. What an inspiring accomplishment. I just got your blog from a mutual friend, and I'm getting caught up on all of your journal entries. I'm thinking of you, my friend.

—Archon Fung, July 28, 2018

## Waiting for randomization

*July 28, 2018*

As expected, the results of my latest bone marrow biopsy indicate that my leukemia is still refractory, so I have been entered into the clinical trial for the IOMAB-B treatment. The next step is randomization into the treatment group or the salvage group. I'm not anxious about this -- the salvage group provides the treatment I would have gotten if there had been no clinical trial, and if I remain refractory after that treatment (which is likely given the profile of my disease), I would then get the new treatment, either outcome leads ultimately to the IOMAB treatment. My preference is to go directly to the treatment group, but I won't be deeply disappointed if I don't.

### Comments

Sending happy randomization thoughts!

*—Josh Wright, July 28, 2018*

Sending good vibes for the randomization. Abrazo from Argentina!

*—Rodolfo Elbert, July 28, 2018*

Hi Erik

all my love!! Marvelous walk the other day. When you fell like, just call me to join you in the walk.  
love  
Boa

*—Boaventura Santos, July 28, 2018*

Sending you all the positive vibe and energy I have with big hugs and much, much love!!!

*—Masoud Movahed, July 28, 2018*

All of us sending support, peace of mind, and love from around the globe as you are navigating these waters. We are here with you, with constant thoughts and prayers.

*—Isabelle F., July 28, 2018*



## My mother

*July 29, 2018*

During the past few weeks I decided that since I was in Madison, I would start visiting my mother in person rather than just talk to her on the phone. I had been hesitant to visit in person since I am avoiding going to public places in order to minimize exposure to germs, but with mask on face, repeated hand washing, and a conscious effort not to touch my mouth or eyes, I decided the risks were pretty low.

My mother, Beatrice, is over 100 years old, or as I will tell her later today when I see her, 5,242 weeks old. [She was born December 16, 1917. At her centenary birthday party on Saturday, December 16, 2017, I incorrectly had candles on her cake announcing that she was 5200 weeks old, forgetting that a year is not really 52 weeks long, but 52 weeks + one and a quarter days long. The formula for a leap year is any year that is divisible by 4 but not by 400, which means that the year 2000 was also a leap year. In her century she had 25 leap days. I had the correct number of days reflected in candle numbers: 36,525, but not weeks. She was actually 5217 weeks + 6 days old on her birthday. On the next day, Sunday, December 17, she was 5,618 weeks old. Since then, when I visit her on a Sunday I tell her how many weeks old she is. Today is a Sunday; she will be 5,242 weeks old.]

In the months since her birthday last December, she has been in slow decline, but until recently basically pretty stable. She is in the intensive supervision unit in a good assisted living facility and also has hospice care support. I am very happy with the care she is receiving.

Ten days or so ago it became very clear that her condition was significantly deteriorating. The hospice nurses, who know a lot about the physical signs of end-of-life, told me that we were approaching the end. So, now I try to visit her at least once a day. Sometimes these visits are pretty easy. I hold her hand. I tell her about my grandchildren, about my book, about her own research and contributions, about how much I love her. She acknowledges what I say with a smile, a nod, and sometimes words. A few days ago when I told her the title of my book was "How to be an Anti-capitalist for the Twenty-first Century" she said, "Good title." Other times, the visits are hard. Her breath is uneven, she is mostly unresponsive, her eyes are closed and she seems uncomfortable. I still talk to her (through a pocket speaker connected to over-the-ear headphones) and say much the same things I would say when she is responsive, but I am not sure how much she actually takes in. She is fading away. She has lived a long and fulfilling life, powerfully shaped my values and intellectual capacities and the kind of person I am, and

has made the world a better place. She is still clinging to life, but slipping. I feel that when I leave Madison for my next round of treatment in Milwaukee, that I won't see her again.

It is, of course, impossible for me not to think about the juncture of mother's approaching death and my own uncertainties about the possibility of dying soon. When I am with her I bracket my own condition. I am there to be as connected to her as a still living person, my mother, and I use the time to affirm the reality of our life-long love for each other. But as soon as I leave, I am usually filled with emotions that spill out, intense emotions without clear focus, but bound up with intertwined grief about the end of her life and the possibility of my own death.

On one visit a few days ago when I entered her room, she was curled up on her side in her bed without any clothes. The staff told me that she had been complaining that she was too hot even though the room was cool, and so she had pulled her clothing off. I looked away, feeling very awkward. I hadn't seen my mother naked since perhaps I was a baby. There are no clear norms for such a situation. But quickly I realized the only thing that mattered here was my doing whatever was needed to stay connected. I turned back towards her, pulled up a chair, put her headphones on as best I could and said, "Mom, your Ricky's here. I love you." She stirred and mumbled some kind of acknowledgement. The staff came in and covered her with a light sheet, which while I was there she didn't seem to mind.

When I left and emotions flooded in, the image that came to my mind was of me curled up in my bed a few weeks ago (July 10 post) crying in despair. I don't think I can sort out this tangle of emotions and images in words, but maybe that doesn't matter.

## Comments

Rik,  
Your emotions, as you described, are inherently intimately entangled, not to mention natural. So no need to sort them out cuz.  
Wally

—Wally Rosenthal, July 29, 2018

This is so hard to read, but I'm glad you are telling us about your mom. As you know, Ron and I have each recently lost a parent - my dad (96) and Ron's mom (102). Those last days are so overwhelming and hard even when we remind ourselves that we have been so lucky to have our parents with us for so much of our lives. I cannot imagine how tough it must be to be grappling with your mom's worsening condition while you are also struggling with your own illness. But we appreciate your keeping us posted about all that's going on...

—Mary Jo Maynes, July 29, 2018

It is very hard to read this and not break into tears, dear Erik! I can only imagine how difficult and emotionally-draining it is to see a loved one's physical conditions deteriorate. Sending you much love and bug hugs!!

—Masoud Movahed, July 29, 2018

It sounds like the end of an era. You are doing a great job. JJ

—John Posner, July 29, 2018

It sounds like the end of an era. You are doing a great job. JJ

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—John Posner, July 29, 2018

It sounds like the end of an era. You are doing a great job. JJ

—John Posner, July 29, 2018

So poignant eriki. So vivid and such a confluence of feelings - warm, sad, uncertain. Xo

—Kathy Cole-Kelly, July 29, 2018

## a glitch, blip, bump in the road, but not serious

July 29, 2018

After the blog post about my mother, Joel Rogers came over for our usual Sunday morning conversation. We have done this for over thirty years now. More or less when both of us are in town, we meet. The real utopias project emerged from these encounters, as did our co-authored book, *American Society: how it really works*. Usually we take a walk, but today I just felt too depleted, so instead we took a couple of chairs to the back porch. The day was another summer perfection: low humidity, lower seventies, sunny with a cooling breeze. We talked for an hour about Wisconsin politics, the sociology department, my upcoming treatments. It was wonderful.

When Joel left, I went to bed, but slept fitfully. Marcia took my temp at 11:30, and it was 99.5,F not yet above the 100.4 F threshold that triggers action. We checked it again at 1:30. Now it was 101.3. I called the cancer clinic in Milwaukee, and they wanted me to come in to the 24/7 clinic right away for evaluation. My temp was 101.7 when we arrived, and I'm coughing a bit. The usual blood tests, blood cultures and chest x-ray. So far no diagnosis, but that is often the case. No one here seems especially worried

## Comments

Your equanimity is remarkable. This is not fun.

—Dan Hausman, July 29, 2018

Yes, I second Dan's comment.

—Hillel Steiner, July 30, 2018

## Chapter 2

*July 31, 2018*

**July 30. 3:30, p.m.** I'm sitting in my bed in Froedtert Hospital, Marcia in a recliner beside me. My temperature is down, almost to normal. It peaked at 103 F in the middle of the night, at which point I was given Tylenol. Now, 12 hours later, it is around 99 F.

We've been told that sometime this afternoon we would find out about the randomization into the IOMAB-B clinical trial. That seems to me to be the beginning of chapter 2 of this story in which I am living. Some people think of the experience of an illness like mine as a "journey." I understand the metaphor, or course, but for me, this is more like a novel, with unexpected plot developments and lots of drama. So, soon I will begin Chapter 2.

**July 31. 7:30. a.m.** No one came by yesterday to tell us what was up with the clinical trial. I suspect my fever was the problem, since I wouldn't be able to enter the trial with an infection. My temp is still around 99, maybe I will get the all clear.

**July 31. Noon.** All is clarified. Sort of. We met with the coordinator of the clinical side of IOMAB study. My time line was off. Here is the basic outline:

1. August 7: I sign the consent form to be in the study, understanding the risks, etc. Was originally scheduled for August 1, but there were some unspecified administrative issues.
2. The following week or so: a battery of scans and tests to confirm my physical eligibility, plus the donor logistics are set in motion.
3. Once my eligibility is confirmed, probably around the 20th or so, then I will be randomized and the donor stems cells harvested.
4. If I'm in the treatment group, once the stem cells arrive (end of August, early September) I will receive the treatment infusion -- the monoclonal antibodies with tiny nuclear warheads (Iodine 131) directed at an antigen on white blood cells and hematopoietic stem cells. The first five days of the treatment I will be in isolation in a lead-lined room. The nurses who come in will carry lead shields. And so will Marcia, who also won't be able to stay with me. I may not even be able to have my laptop. Time for a silent meditation retreat.
5. If I'm not in the treatment group, it is straight to the hospital for a fourth round of chemo, CLAG-M. If at the end of the CLAG-M cycle, I still don't have a robust remission, then I enter the treatment group. If I have a complete remission (unlikely) I go to conventional transplant.

And then we are well into the guts of chapter 2: destruction of my bone marrow; repopulation with new healthy, happy stem cells; dealing with infections; cleaning up the remnants of my defective immune system. Exciting. A bit scary. A lead-lined room is pretty cool. I'm hopeful.

## Comments

I wish you the best Erik along with the warmest loving hug.

—*Mansoor moaddel, July 31, 2018*

What are you able to bring with you into the lead-lined room? Are books/magazines approved? Disposable games to pass the time?

—*Josh Wright, July 31, 2018*

It does read like a novel. Fascinating twists and all. Glad you can simultaneously have perspective and hopeful cheer. The idea of paper books/magazines seems great.

—*Myra Ferree, August 1, 2018*

## mini-update (more later)

*August 2, 2018*

Much has happened in the last few days and I want to write about this in detail. I have begun a much more extended account, but am too worn out right now to finish it and wanted to share the basic events on recent days right away:

**Tuesday, July 31.** My mother died in the late afternoon. I managed to be with her for a half hour a few hours before she died and was planning to come back after dinner. It is sad, of course, but she had lead a wonderful life and we knew this was coming.

**Wednesday, August 1.** We spent the entire day in Milwaukee. The visit confirmed that I will be will be officially enrolled in the clinical trial on August 7. I now have a much more detailed time line and better understanding of what lies ahead which I will tell you about later. I mentioned a minor symptom, which lead to

tests which lead to a CT-SCAN which required a six hour stint in the ER. But in the end, any dire issue was ruled out. We thought we would get back to Madison around 12:30. We didn't actually get home until 9pm.

## Comments

Sorry about your mama.  
Glad about the dire. Will wait to hear more.

—Sarah Siskind, August 2, 2018

Sorry about your mama.  
Glad about the dire. Will wait to hear more.

—Sarah Siskind, August 2, 2018

Erik, I'm so sorry about your mom. It does sound like she had an extraordinary life, and it must have meant so much to her that you were with her that day, and almost every day before. Especially with all you've had going on, that's an incredible devotion. I'm glad to hear your timeline has been clarified and things are moving forward. You're in my thoughts and I hope this next stage progresses without complication. love, devah

—Devah Pager, August 2, 2018

We will think of you and Beatrice in her passing.. She was an amazing woman, far ahead of her time. We were fortunate to have known her.

With all our love,  
Susan and Richie

—Susan Davidson, August 2, 2018

Hi Erik,  
I'm really sorry to hear about your mother. That is sad but also good that you were with her so much despite all that is going on with you right now. You are in my thoughts every day and I am so grateful for this site to keep me updated, despite the geographical distance. Good to hear about the trial too. Love to you and Marcia as you navigate your way through all of this.  
Janeen xxx

—Janeen Baxter, August 2, 2018

So sorry to hear about your mom, but we have been lucky to have had parents with us for so long, and I'm glad that you could be with her despite everything. Ron is on the road now (on his way to CA) but I will talk with him soon. The clinical trial starts so soon! We will be watching for your posts.

—*Mary Jo Maynes, August 2, 2018*

I am very sorry to hear about your loss, dear Erik - I know she had a remarkable life and a brilliant academic career herself. I also know she that was always very proud of you - Much love!

—*Masoud Movahed, August 2, 2018*

I'm so sorry to hear about your mom. Your connection with her sounds very special and I can only imagine what it meant to her the you were with her in the final hours. Thinking of you and wishing you all the best in the clinical trial.

—*Sarah Kaiksow, August 2, 2018*

Dear Erik, my condolences to you and your family. Be patient. I am happy to hear that you are in clinical trial.

—*Mansoor moaddel, August 2, 2018*

so sorry about your mom -- as you say, we do all have to go sometime and she had a long and fulfilling life. Still, it must be hard for you and Marcia to deal with those emotions along with the roller coaster of your own treatment. Wishing you and your family the time and space to grieve, if not now, then later.

—*Myra Ferree, August 2, 2018*

Dear Erik,

I'm so sad to hear about your mother. We send you and Marcia our condolences. We also are sending you good thoughts as you receive your new treatment. Warmest hugs, Joan and Kjell

—*Joan Fujimura, August 3, 2018*

Dear Erik,

So sorry to hear about your mother. Deepest condolences from AJ, Yeonhee, and me. And wishing you all the best with your new treatment.

—*Chaeyoon Lim, August 3, 2018*

Glad you have a couple days at home. Sorry to hear of your loss - no matter the age the loss of one's mother is profound. Wonderful you had time together. Congrats on motion forward Aug 7. Sending wellness & seeing you back on campus before the new year. Jody

—*Jody Whelden, August 3, 2018*

Querido Erik, I am very sorry for the loss of your mom. I send you lots of strength and good wishes for the new phase of the treatment. We are thinking of you a lot here in Argentina. Abrazo.



—Rodolfo Elbert, August 3, 2018

## Elaboration of medical Update from August 1

*August 4, 2018*

It seems with every visit to Milwaukee I get a clearer sense of the steps ahead. I am sure that I will get another dose of greater precision at our next consultation there on August 7 when I formally sign the consent to participate in the study. At that visit I will have an extensive session with the study coordinator who will, I am sure, explain everything.

I have met all of the eligibility criteria that are connected with my disease -- mainly repeated failures to get a satisfactory remission -- and so on the 7th I will sign the consent agreement. This does not yet fully enter me into the study, since I still have to meet the full eligibility criteria for the stem cell transplant itself. This requires a series of tests over a couple of weeks of heart, kidney, liver, lungs and other issues. This will still be outpatient, so I will be living in Madison and coming to Milwaukee periodically for the tests. Once this is all completed, and the donor's health status is confirmed, then there will be the formal randomization. I don't think there is a precise date for that, but it will probably around August 20-24. If I'm in the treatment group, then the provisional date for my admission to the hospital for the transplant will be September 6. Until then I would be in Madison. If I am in the salvage group, then I will enter the hospital at the time of randomization for the CLAG-M chemo treatment for one more attempt at getting a robust remission. That will involve, as in April, 28 days in the hospital. If I remain refractory, then I cross-over to the treatment, with a transplant slated for October.

### Medical Misadventure in Milwaukee

The anticipated plan for our visit to Milwaukee on August 1 was labs at 10:20 followed by consultation with Dr. Laura Michaelis, and then back on the road to Madison by noon. This plan got disrupted because I discussed a symptom. Here's the story: At the previous consultation with Dr. Michaelis, I had mentioned a symptom that had occurred on two separate occasions, but then disappeared. On two occasions at night, my vision dimmed to the point that lights in a room looked like they were half dimmed by a dimmer switch, and when I entered my bedroom with the lights turned off it felt like entering a cave in which I couldn't see much of anything, e.g. outlines of bed etc. There is enough ambient light from the hallway night light that normally I see clearly the outline of the bed. But on these two occasions, I could see absolutely nothing (except for a red LED light on a recharger). The first of these episodes had occurred about three weeks earlier, the second a week or so later. The first was much more prolonged-- it lasted all night; the second only for a few hours. (I could tell how long because of waking up to change t-shirts due to night sweats). Dr. Michaelis said I should make an appointment

with my ophthalmologist in Madison, which I did. Only, I had to cancel that appointment because of being hospitalized with fever in Milwaukee. I mentioned this to Dr. Michaelis at the end of our time. She said she still wanted this checked out and would see if I could get squeezed into the schedule at the Eye Institute at Froedtert.

So, back to the waiting room. Half an hour later we were told one of the retinal specialists there could squeeze us in. We went over to the Institute, which was in a different building. More waiting, but really not too long. First I had a thorough eye exam, and then a more specialized exam involving some fancy retinal photos. Back to the waiting room, this time for an hour or so waiting for the doctor to find time to come in, look at the results, and discuss things with us. When she came in, looked at the pictures and heard my account of the symptoms she said that the main thing to rule out, then, was a vascular blockage in blood supply to the eyes, since that would affect both eyes at the same time. This would require a CT-SCAN, which meant we had to go to the Emergency Department. Off we went.

The Froedtert ED is what one would expect in a hospital in a big city: filled with sick people, some police officers, quite crowded. This is not where I wanted to hang out for immunity reasons. We moved over to the corner of the lobby where the wheelchairs were stashed and sat in wheelchairs, a good distance away from the other patients. The ED process is what one would expect: long waits; then admission to a private room (which made things much calmer) and getting hooked up to an IV; then more waiting; and finally after several hours, the CT-SCAN, followed by more waiting until the results were read. Finally the doctor came in and said that the good news was that everything was negative -- no vascular problems. She just needed the ophthalmologist on call to look over the results and we could go home. Half an hour later a nurse bounded in cheerfully saying I needed another blood draw because the ophthalmologist wanted two more tests -- a C Reactive Protein test and an ESR test (whatever those mean). It was already approaching 7 pm. I really didn't see the point in this. I explained that I had just had a blood draw that morning in the cancer center and was having a blood draw in Madison on Friday the 3rd and these could just be added to the other tests being done then. The nurse said he had to get the floor doctor to approve this. The floor doctor paged the ophthalmologist. More delays. But eventually everything got sorted out. I was disconnected from the IV and we headed home. We got back to Madison about 9:30 pm.

## Comments

I am so glad to hear about the good news, dear Erik! looking forward to hearing more good news in the coming days. Much love!

—Masoud Movahed, August 4, 2018

Jeeps

—Sarah Siskind, August 5, 2018

Hi Erik, Norma and I got back to Madison on Friday and are heading off today. I was sorry to hear about your mother's death. I know she was very proud of you and that you were a very good son to her. We get back to

Madison on the 15th. Hope to see you then.

—elliott sober, August 5, 2018

Dear Erik

My sincere condolences for your mother's death.

When I was young I was a devout catholic. I have returned to this gone experience just to pray for your health. I am sure you will get better soon.

Love

Boa

—Boaventura Santos, August 5, 2018

## Beatrice Ann Wright, December 16,1917 - July 31, 2018

August 5, 2018

My mother died at 6pm on July 31. I had been hospitalized in Milwaukee for a fever for two days and was getting an infusion for low phosphorus when I got a call from hospice that she was near the end. Marcia told this to a nurse in order to expedite the discharge process, and the nurse checked in with the doctor on the service who said that the infusion could be halted; it wasn't an emergency. We left the hospital at about 2 p.m. and got to the Ivy Floor at the Terraces (my mother's assisted living facility) at 3:30.

Marcia lifted my Mother's head to put on the over-the-ear headphones and I spoke into the pocket speaker. I don't think she could hear me, but one never knows what might get through. Her breathing was very erratic, sometimes with long pauses, and there was a loud rattle-sound at the back of her throat. I knew the expression "death rattle", but had never encountered it. I held her hand, and spoke to her about her wonderful life and how she would live on in her children, grandchildren and great grandchildren. But mostly I talked about our love for each other.

I left after half an hour or so and said I would return after dinner. Hospice called just after 6 to say she had died.

I thought that since I have been talking about my mother from time to time in my postings, and since not all of you who are reading this knew her personally, that I would spend some time talking more about her and her life. (I just noticed, reading this, that I spontaneously wrote "talking" here, rather than "writing". I think this reflects how I am experiencing what I am doing here -- I am talking with my friends and family, people who care about me and whose connection is meaning so much to me now). I will refer to her as "my mother" rather than

"Beatrice" in writing about her life, especially because of the emotional fullness of the moment. (Some of what I write may repeat some things I've said in earlier blogs, but I won't worry about that.)

My mother's parents, Sonia and Jerome Posner, were Russian Jewish immigrants who arrived in New York in 1911. They initially lived on Staten Island but soon moved to Jamaica, part of Queens. Her older sister, Esther, was born in 1914, and my mother and her twin brother Sydney followed in 1917. She was politically active in high school in the early 1930s, participating in social justice activities and once getting thrown out of an honors society for handing out leaflets in support of a janitors' strike at the school.

She went to Brooklyn College at age sixteen where she studied psychology with eminent humanistic psychologists of the era, Solomon Asch and Abraham Maslow. The commute from her home in Jamaica, Queens, was pretty arduous, and so one of her professors offered her a room in his house in exchange for occasional babysitting. The baby's name was Olin. This, the source for my middle name: a baby named Olin in mid-1930s Brooklyn.

After graduating in 1938, my mother entered graduate school at the University of Iowa to study under Kurt Lewin, a German refugee psychologist who lead a very energetic circle of psychologists in the 1930s and 40s in a theoretical perspective called topological psychology. My mother always used to refer to a saying of his, "There is nothing so practical as a good theory." In graduate school she married a fellow student studying under Lewin, Martin Erik Wright. (He was always called Erik). He got his phd a year before she did and took a job as an assistant professor at Ohio State University. When the Dean of the College of Arts and sciences found out that her husband was beginning a new job as a professor, he refused to allow my mother to register for classes. As we were told the story, he said to her: "Your place is by the side of your husband. He needs your support." Kurt Lewin intervened and got the Dean to allow her registration, so she continued her education.

During WWII my Dad was stationed as a psychologist in the Navy in California. My mother had begun a job at Swarthmore College, but decided to join him in 1943. There she became involved in research and support projects involving wounded soldiers. This lead her into the subject of psychological aspects of physical disability, which would become her life's work.

After WWII my Dad entered medical school on the G.I. Bill to become a psychiatrist. My mother's parents moved to join my mother and her growing family (Colleen born 1945, me in 1947, and Woody in 1949), and their help made it possible for my mother to continue research and some teaching. In 1951 we moved to Lawrence, Kansas, where my father became the head of the clinical psychology program at KU.

My mother was not allowed to have a job in the psychology department at KU, because of anti-nepotism laws which blocked spousal hires in the same units of the university. In the 1950s, therefore, she primarily did research at the Menninger Foundation in nearby Topeka, Kansas. Those laws changed in 1960 and she was immediately hired into the Psychology Department, where she worked until she was forced to retire at age 70 in 1987. (Mandatory retirement rules were still in place in the 1980s).

Her most important book was published in 1960, *Physical Disability: a Psychological Approach*. A second edition -- which was really a very major revision and development of the ideas -- appeared in 1983 under the

changed title, *Physical Disability: a Psychosocial Approach*. Both books were included in the list prepared by the American Psychological Association of the hundred most influential psychology books in 20th century. There are lots of ideas in the book on all sorts of specific topics, but the heart of the book's argument I think can be distilled into three central themes. First, in studying physical disabilities it is always crucial to fully understand the perspective of the person with disability, to see the world through their eyes and experiences. Second, the impairment of functioning in the world is as much a question of the disabling conditions in the environment as the the physical disability of the person. As she once told me, a heavy hard-to-open door makes most people disabled. The absence of curb cuts dis-ables a person in a wheel chair from mobility (and also people pushing baby carriages). And third, values are critical in understanding the conditions of physical disability.

My father died in 1981. This was very tough on my mother, but soon she mastered all of the things that my father had taken care of. Shortly after my father died my brother Woody "lent" his dog Tenny to her to be a temporary companion, but before long it was clear that this was a permanent arrangement. Tenny's full name was Tennessee Street House, in honor of our childhood home. Tenny was my mother's constant companion, spending his days in her office at the University. At one point, when it was noted that dogs were not allowed in campus buildings, the faculty Senate (I believe I'm identifying the correct body), voted to make Tenny an honorary faculty member.

My mother continued living on her own in Lawrence until 1994 when she began to have some significant vision problems and decided to move close to one of her children while she was still physically active. Madison was the place most like Lawrence, and so she moved here. For the first ten years she lived in a condo, but then moved to Capitol Lakes, a wonderful retirement community in the downtown area of the city. She did some teaching at the University of Wisconsin in the Rehabilitation Counseling program and for a while continued writing as well, but mostly she was retired.

She made a real life for herself in Madison for almost a quarter of a century, with new friends and many activities, including a kayaking expedition in the Apostle Islands in her 80s. My family was an important part of her life here, but for the first fifteen years or so she really was independent, even with her failing eyesight. Since 2004 (I think) she lived at Capitol Lakes, first in a beautiful independent living unit, then in assisted living, and finally in the intensive supervision unit of assisted living until her death this week.

Well, that's a basic, skimpy narrative of my Mother's life and career. Here are some more personal thoughts and memories.

It is pretty obvious that the kind of person I am was deeply shaped by my mother. Both she and my father were enthusiastic promoters of "projects" for their children -- science fair projects, special school projects, art projects. At dinner we would always be asked about what we were doing in school and encouraged to really talk about things we were learning. When we were older, this would sometimes be like a little seminar. Growing up, my mother read every paper I wrote, and by high school this meant that she was functioning really like a writing tutor. One thing she told me that I now tell my students is that I should learn to write in such a way that my critics would know accurately why they disagree with me. Education and intellectual pursuits, pursued with seriousness and excitement, were at the heart of the family culture cultivated by my mother.

There is something a little more specific than simply the high value placed on intellectual pursuits and passions. My mother celebrated creativity. When one of us would do something with some kind of creative spark to it -- a clever solution to something, a beautiful imaginative drawing, a story we wrote which was not just a standard kids product -- she would get really excited. She would be happy and supportive about everything; but when there was something with a more quirky character, she would marvel at what we produced. Each of us kids have stories to tell about this, but for me there are a few of my childhood projects and productions that I really remember how enthusiastic she was. Here's one. In grade school I had a really wonderful friend named Johnny Vequist. [He subsequently went to West Point and then defected to Sweden during the Vietnam War in protest to the war]. We started a newspaper in Cordley School, I think in 4th grade, called "The Muskamadolly". I don't remember where the name came from, but the newspaper always had a picture of some strange creature, which were the maskamadollies. Johnny was the real artist -- really a spectacular, imaginative artist of strange concoctions. In fifth grade we collected these pictures into a book called "Creatures of the Solar System". I wrote the text; Johnny did most of the illustrations. My Mom was ecstatic about this volume, and would show it off to her friends. I felt cherished and validated.

Half a century later in Madison, my mother's apartments were adorned with framed pictures done by the three of us when we were children, along with many magnificent mature paintings by my sister who became a professional artist as an adult. Her condo and then the apartments at Capitol Lakes always had Navajo rugs on the floor which my Dad collected in the 1950s, a beautiful Japanese silk panel painting on the wall, and then dozens of drawings, paintings and artifacts from our childhood.

Of course, things were more complicated as well. My mother could be very judgmental and was also completely certain about her judgments. Her motives were always good: she wanted to make me a better person in one way or another. So she would make suggestions about how I could improve something, where the distinction between giving advice and an instruction could sometimes get quite fuzzy. As a child this could get quite annoying, as I suppose it does for all children. When we would get into arguments, sometimes she would reject my views on the grounds of my "tone," saying "it's not what you say but how you say it." There may be some truth in that, but it was very frustrating to me when in my view I was right about something and arguing with her about it, and then she would invoke this as a way of cutting off the discussion.

As an adult, this tendency for my mother to be absolutely certain she was right about something, give unsolicited advice about it, and then insist that I needed to have a good argument against her advice continued:

- We have city recycling bins stashed at the side of our house, visible from the street. My mother felt that this was unsightly and we should build some kind of attractive wood housing for them. I didn't think this was necessary. But this is disrespectful to your neighbors, she would say. I doubt if anyone even notices, I countered. She wouldn't let it drop, but would bring this up time and again. I would somehow have to have taken a survey of neighbors to see what they thought to provide the needed evidence.
- On peeling carrots. My mother insisted that most of the nutritional value of carrots were in the skin, and therefore one shouldn't peel carrots. Dozens of times over the years we were told not to peel carrots.



- Marxism & Socialism. My mother, of course, was very proud of my academic achievements, but she never could accept that I used the word "Marxism" to describe the theoretical tradition within which I worked or the word "socialism" to describe the alternative to capitalism for which I argued. I explained many many times why I felt it was important for me to use these words and that part of my goal was to transform some of the meanings connected to them. She wouldn't buy it. "Rickey," she would say, "Marxism and socialism will just put people off. Don't use those words."

I remember one notable occasion after my mother moved to Madison where she ultimately admitted that maybe I was right on one of these kinds of disagreements. She always made very weak coffee. When she would visit me, she would say that weak coffee was just as tasty as strong coffee. Taste was just a matter of what one was used to. And weak coffee was much cheaper. I would argue that some things really did taste better even though it might take some time to realize this. Well, after a decade or so in Madison I mentioned to her that the coffee she brewed at her house was pretty strong. She said, with a smile, I guess I have grown to like it better.

Well, no need to go on with more examples of this. Mostly, especially as I got older, I was pretty good at just going with the flow and not getting too annoyed by episodes of unsolicited-advice-that-you-must-follow-or-I-will-keep-reminding-you-of-them. In any case, in the last years of her life, the unsolicited advice declined (except for my use of the words Marxism & Socialism -- that came up in the last year again).

A few months ago we had an exchange which I think may have been her last effort at improving something I said. On one of my visits I said something like this to my mother, "Mom, you know, in certain fundamental ways our research is the same: You studied people with disabilities; I study society with disabilities. You always looked for the positive potentials within people with disabilities that would enable them to transcend those disabilities; I always look for the potentials in society with disabilities. And you know, the bottom line for both of us to promote human flourishing." She replied: "Rickey, I like the expression 'human flourishing.' But don't say, 'bottom line.' The word 'bottom' will make people think this is less important. Say 'fundamental'". I said, "you're right. It is better to say that the fundamental thing is the value of human flourishing." Twenty years ago I would have rolled my eyes and said something like, "Mom, no one will interpret the word "bottom" in the expression "bottom line" to mean at the bottom." But now I felt in my heart: yes, my mother is still here, and I celebrated her suggestion.

The very last conversation I had with her about my work in which she gave a real reply even though she could barely talk, occurred just a few days before her death. (I reported this in a posting on July 29). I told her the title of my book. She commented, "Good title". Writing this now makes me cry.

## Comments

Thank you so much for sharing these lovey memories. Now, I know!

—*Mansoor moaddel, August 5, 2018*

Reading this made me laugh and cry. We come from very similar backgrounds. Thank you for adding such

richness-of-feeling to my Sunday morning, Erik.  
With lots of love...

—*Rachel Schurman, August 5, 2018*

Thank you for sharing. Reading this made me cry as I think about the love between me and my son. He is only 6, but I hope to have as wonderful a relationship with him throughout my life as you had with your mother.

—*Sarah Kaiksow, August 5, 2018*

I love these memories! What a fantastic life story she has created for you to share. I am humbled to have met her, and always grateful for you and Marcia. Xoxo

—*Heather Crowley, August 5, 2018*

I can't help crying, too. You write beautifully.

—*Marianne Ahrne, August 5, 2018*

This is truly incredible eriki. Thx for giving such a total picture of your mom. Xo

—*Kathy Cole-Kelly, August 5, 2018*

What a wonderful story,. Eriki! My Narrative/medicine workshop started today and so I have been thinking and talking about life stories. I really appreciate your writing this beautiful one about your mom .

—*Mary Jo Maynes, August 5, 2018*

It is impossible to read this and not break into tears. These are beautiful memories and thanks so much for remembering - and indeed, in her remembrance does your heart find rest in this challenging time. Only a mother of her caliber can imbue a wonderful son like you with such an intellectual verve and excitement that motivate your exquisite scholarly work. Much love!

—*Masoud Movahed, August 5, 2018*

Erik --

As I expect you can tell, this is my first visit to your site, in spite of the fact that I had encouraged you to create it. I can see that you are making very good use of it, and I hope that you feel the same.

I recall meeting your mother some years ago and being very impressed with her -- especially in a discussion of deafness, which had extremely hampered my Dad's life chances -- and now affects my life as well. Your brief account of her long life was a wonderful read.



Congratulations on completing your book, in spite of all. That three-paragraph summary is powerful.

But the important thing is my hope that, despite the obstacles that you are facing, your treatment and recovery will be successful.

Best wishes,

Bob

*—Bob Hauser, August 6, 2018*

Rik,  
Thank you very much for the wonderful tribute to your remarkable mother who, I have always been proud to say, was my aunt. Reading it over several times brought back more and more warm memories of her. She and I did not meet as often as we would have if we had lived closer to each other. Nonetheless, she was a very important part of my life. I can remember many interesting conversations with her from the time she was about 40 (and I was about 7) up until a few years ago. She gave me the kind of nurturing support that you describe her giving to her children. Her praise for any of my accomplishments always made me feel very very good, even after I had become an old man.

Luckily for me and my family, she came to our city, Toronto, in 2009 to receive the Kurt Lewin Award from the Society for the Psychological Study of Social Issues. My family and I really treasured that time with her. Two things particularly stand out in my memory of that visit. First, her acceptance speech. She gave a very interesting and entertaining overview of her and others' work during the previous 60 years on how to assist people with disabilities. Your mother was over 90 at the time but she looked and spoke like a 60 year old who was in her prime. Another strong memory I have of that visit is something that happened at the airport while she and I were walking towards her departure gate. She asked me "Can you skip?" I said, "I don't know. I certainly have not tried to in many years." "Can we try?" your mom asked. I said "okay" and then we held hands and (more-or-less) skipped along the corridor, to the amusement of the hundreds of people we passed.

The last time I saw your mother was at the party that you organized for her hundredth birthday. She was then much diminished. But her essence still came through. She really rose to the occasion.

I am very grateful to your mother.

I loved your mother very much, and I still do.

*—Peter Rosenthal, August 6, 2018*

Erik:

Thank you for sharing this wonderful post about your mother. I have been lurking at the site for months, often moved and inspired by posts, but today I cried along with others at your heartfelt comments and had to respond. Keep up the hard fight and know there are many of us out there with you. My love to Marcia and the rest of the family.

—vern baxter, August 7, 2018

Dear Erik,

So very sorry about your mother's passing, but what a touching tribute you have given us about her. It is clear that you had a very special relationship. Your words are moving -- both heartwarming and sad.

And thank you for sharing so openly about all you are going through in your treatment. Your honesty, humility, openness, and keen perspective are all really powerful... I have been reading your posts and have both laughed and cried and just generally appreciated anew what an amazing person and observer of life that you are.

We are all pulling for you! Hope you'll be back around the UW Soc department very soon.

With warm wishes,

Marcy

—Marcy Carlson, August 8, 2018

Hi Erik,

My condolences. Your mother seems to have been an extraordinary person.

(My first visit here for months as you can tell).

Keep up your good spirits — we are rooting for you from Gotland (and soon again from Värmdö.

Stefan and Erica

—Stefan Svallfors, August 13, 2018

## Medical updates: beginning eligibility tests for clinical trial & new sources of fatigue

August 8, 2018

### Clinical trial

On Tuesday, I signed the consent forms for the clinical trial. To be actually accepted into the trial, I now have to pass a number of tests to confirm my physical eligibility. Today I had an EKG, echo cardiogram, and four pulmonary function tests. Next Monday, the 13th, I will finish off the tests. The only genuinely weird test -- which I had not known about until this consultation -- is that I need to be tested for the presence of "human-mouse-antibodies". This is very rare, but if I have such antibodies in my blood, then I will be dropped from the trial. I don't really know what human-mouse antibodies are or how you get them. I think it makes you ineligible for the treatment because the antibodies developed for the IOMAB radioactive treatment are developed using

mouse cells, so if I have antibodies to mouse cells, the treatment fizzles. I'm not worried.

If I pass all the tests, then I will be randomized on the 20th and then we will know for sure the schedule for the next couple of months. I did get one nice piece of additional information: my donor is a 31 year old woman in the United States.

### **Fatigue**

In this phase of my treatment, when we are no longer trying to get a robust remission, there is a new source of fatigue. The cause now is not simply low hemoglobin, but a rise in leukemia cells (blasts) in my peripheral blood. This is to be expected since my disease has been untreated for three weeks. On Monday morning I felt totally depleted and was sure that this indicated a low hemoglobin level well below the threshold for a transfusion, but in the lab results my hemoglobin was a happy 8.3, above the threshold. What had changed was that my white cell count and blast count had in fact risen very rapidly from the previous Friday. The solution is to take oral chemo, Hydroxyurea, which is mostly used in chronic myeloid leukemia to reduce the number of white blood cells (and thus leukemia cells) in the blood.

I began taking these pills on Monday and already the numbers are moving in the right direction. Unfortunately, the drug has also triggered a re-emergence of my upper respiratory cough. This has produced two nights of very disrupted sleep. Last night I moved down to the living room couch in the middle of the night so Marcia could get a better night's sleep. Since I don't want to take the cough medicine that is most effective -- because of the codeine -- I'm left hoping that the cough will subside as my body becomes familiar with this new medication.

## **Comments**

I am very sorry to hear about the new source of the fatigue and also the coughing, dear Erik - Here is hope that your body gets used to the new medication very soon, so that the coughing comes to a full halt. Sending you a big hug and love!

*—Masoud Movahed, August 8, 2018*

A little codeine under the circumstances seems like a sensible step to me. Are there side effects to that I am missing?

*—Myra Ferree, August 8, 2018*

I concur with Myra, coughing is very fatiguing as I know from personal experience. I think taking codeine for a short period should not be too dangerous.

*—Marianne Ahrne, August 8, 2018*

Hugs!

—SARAH S, August 8, 2018

## a moment of bliss

August 9, 2018

Becky, Adriano, Vernie (2 and a half) and Ida (2 months) are visiting for a few days. They arrived while I was having a transfusion of two units of red blood cells yesterday. I had had two miserable nights of persistent coughing, although I must have slept some, but was very tired. The two units perked me up a bit, enough to warmly meet my new grand daughter Ida for the first time, but quickly over the course the afternoon and into the evening my limited energy faded. The worst part of it was feeling that my emotional energy to just be in the moment and relish the two children was so low. I felt very discouraged. This visit felt so important to me because of the uncertainties ahead, but I could not marshal up any reserves of energy to be fully there.

I went to bed early and decided to add two Benadryl tablets to the two cough medicines I was already taking. Perhaps drying up everything would reduce the coughing, and in any case two Benadryls might help me sleep. It worked. I even had minimal night sweats (two t-shirts). Maybe anti-histamines interfere with whatever is the night-sweat mechanism. In any case, I slept really well, no coughing, and woke up refreshed at 6:30.

Becky was in the living room with Ida and Vernie. We hung out, connecting properly. At one point I was holding Ida in my arms with her head nestled in my shoulder next to my chin. I walked out onto the back porch to see what the weather was like, and then down the back steps into the back yard. Warm sun, cool air, bare feet in the dew-laden grass. Vernie came out with Becky to join, wearing his wonder Woman t-shirt us and nothing else and started running around yelling "I'm running in the grass." Becky chased after him. I wandered slowly around the yard, holding sweet, two-month old Ida. She was relaxed, semi-sleeping, with her arms draped over my shoulders. Tears rolling down my cheeks.

## Comments

A moment of bliss, indeed!! So beautiful and touching - Sending you all big hugs and much love!

—Masoud Movahed, August 9, 2018

Goosebumps and tears reading this, Erik. So happy for all of you.

—Cathy Loeb, August 9, 2018

Erik --

A moment of bliss, indeed.

BTW, my take has long been that Benadryl is the second best medicine known to humankind. The first, of course, is aspirin.

That is, if you don't count the Placebo Effect.

Best wishes,

Bob

*—Bob Hauser, August 9, 2018*

This is so lovely to read. Huge hugs to you.

*—Tom Malleson, August 14, 2018*

## All together

*August 11, 2018*

If five years ago, before my daughters had children, someone asked me, "What is your fantasy of what it would be like if Jenny had a three-year old and Becky a two and three quarter year old and a new baby, and they all visited you on a beautiful summer day in August?" I would have described my actual day today (without, of course, the small detail of my having leukemia):

This morning, around 7:30 a.m. Safira tip-toed into our room and said "Hi Dadoo". Jenny, Mark and Safira arrived around four in the morning after a 16-hour drive from Colorado. Marcia had greeted and settled them in while I slept. Since Safira had slept quite a bit on the ride, she was up early while Jenny and Mark slept in. "Hi Sweetie. Let's go downstairs and let Gaga sleep." I had had a really good night's sleep and was ready for action.

Becky, Ida, and Vern were in the kitchen hanging out. Vern and Safira greeted each other, sat next to each other at the table having some minimalist breakfast, and then started chasing each other around the downstairs circuit: kitchen to dining room to living room to entry foyer to kitchen. Running full steam, shrieking, occasionally stopping for a mouth full of applesauce bread. Becky gave Ida to me to hold. Beautiful commotion. They

stopped for some refueling. Orange Juice in plastic sippy cups. The two of them looked at each other, held up their respective cups, touched them together and said "cheers". More running around the circuit. Endless joyful energy. Then again at the table. Vern asks me to sing my song, so I sing to all three of them together for the first time, "I've got three Grandchildren all a delight..." (see my June 27 post for the song).

At 9:30 we're all dressed. Adriano, Becky, me and the three kids walk to Vilas Zoo (ten minutes from our house). It is warm and sunny and a bit humid, but very pleasant. The kids hold hands as we walk. At the zoo, the first event is to ride the zoo train, which Vernie was very keen on. Then the kids played together on the enormous zoo climbing structure and slide, with Adriano trailing after them.

I begin to fade, alas. Jenny has joined us, and Safira too is tired, so by 11:00 the three of us head back home.

It is now about three. I slept for a couple of hours. The kids are just getting up from naps themselves. My family is all together. Vernie and Safira are having good, happy fun together. I'm feeling at ease, once again, in my body after good rest. Things will be Okay.

## Comments

So wonderful! Hugs to everyone!

—Mary Jo Maynes, August 11, 2018

I think this is what "they" mean by ... "living in the moment". May you have many more days like this one! xx Janet

—Janet Gornick, August 11, 2018

Erik —

Sitting next to Bob Hauser at the ASA  
in Philadelphia — and just learned about this disease! I will write more tomorrow, but just wanted to send my STRONGEST  
WISHES for a healthy, happy recovery!  
Lots of love,  
Barbara

—Barbara Heyns, August 11, 2018

I am so delighted to hear about the beautiful and emotionally uplifting moment of family reunion! Sending you all big hugs!

—Masoud Movahed, August 11, 2018

This post brought such joy. I am so happy that you are all together! I am inspired and so touched by your presence and attention to the bounty in front of you at this moment. Sending much love to the whole Wright family who were such a part of my family growing up!

—*Amelie Davidson, August 12, 2018*

Sending everyone warm wishes! What a wonderful family day!

—*Josh Wright, August 12, 2018*

So happy the whole crew is together! Can almost feel you there! Love to you, Erik, and all! Rosi

—*Rosi Gowdey, August 12, 2018*

Dear Erik,

I start reading here soon after the death of your mother. Your writing about her has triggered a flood of memories and feelings. (I am grateful to Peter Rosenthal for letting me know about the situation you are facing.) First about your mother and her family around her. The year or two before you were born in Berkeley I remember family visits where our family would drive from Stanford to Berkeley for an afternoon or evening to visit Bea and Erik. I was seven or eight and what sticks with me is the warm and welcoming atmosphere, the great friendship of my parents with yours, and the music. It was folk music records: Burl Ives and Woody Guthrie. I know now, of course, that the family friendship began earlier in Iowa City and that the teaching and dynamism of Kurt Lewin created a lasting force field and that under that influence Beatrice and my father, Roger, collaborated on their important book on Adjustment to Physical Handicap. But for seven-year-old me it was the warmth and liveliness of Bea and the Wright household that I imbibed.

That sense of your family only deepened in the 1950s after Bea and Erik joined my father at KU and your family now included very active kids. Again visits to your family in Lawrence were a treat for a young teenager (who was sometimes enlisted to look after the Wright children while the grownups went out). There were games, and projects, and music. There was usually a toy or gadget that demonstrated some scientific principle and led to an animated discussion. Your father projected a sense of how good it is to be alive and interested in the world of nature and of people. There was so much to learn and to see, and it was fun, not hard, to do it. Those experiences of my childhood left a lasting mark. When visiting my parents in Kansas after Nancy and I had our own family we often stopped to speak with Bea. She was always interested in news of our family and we enjoyed hearing about what you and Colleen and Woody were up to and what she herself had going on. I am glad we had the occasion to visit Bea in Madison. Your description of her room with pictures from your family past and present and the Navajo rugs your father collected rings true. She was very proud of you (and of Woody and Colleen) and eager as ever for family news about us. And full of ideas about what made a good living place for seniors like her. I here can reveal that she gave me a fine collection of bolo ties from your father's collection, some of them with motifs that surely connect them with the Navajo rugs.

So you can see that Beatrice and Erik and your childhood family made on me a lasting impression. I, too, had a wonderful mother who lived beyond 100 years, but Bea added her special kind of loving motherness to my experience. I thank you for writing so directly and lovingly about her.

There is more to say about getting acquainted with you as a grown person and admiring the content and

direction of your academic work. One of the pleasures of reading your reports about your experience now is that it brings me more deeply and currently in touch with your amazing family circle. Your indication of how meaningful that circle is resonates with my own experience. Please know that I am part of that larger circle of people who care about you, share the hope your treatment will succeed, and want you to keep these reports coming. Jonathan Barker

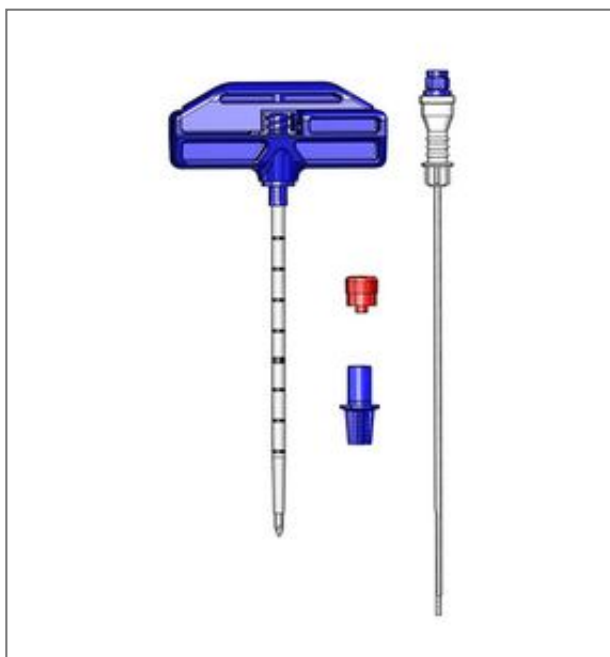
—Jonathan Barker, August 13, 2018

Tears of love and joy come to my eyes as I read about your morning with your beautiful children and grandchildren, Eriki. So much love surrounds you and you bring to the world. Love to you and see you all soon!  
xoxo

—Lisa Baker, August 14, 2018

## Medical Update & mini-tutorial

August 14, 2018



Numbers numbers numbers. Tracking numbers becomes a preoccupation of cancer patients. Different kinds of numbers: many kinds of proteins, specific blood counts, temperature. In one way or another, there are numbers that tell us what is happening with our disease. Numbers come mostly (I think) from blood tests. You get a



blood draw, and then you wait to see what Your Number is, what it is doing.

For a long time I was mostly preoccupied with "Absolute Neutrophils". Neutrophils are the type of white blood cells that do the most to fight infections, so a low count makes one especially vulnerable. That will be the problem I face when I get the stem cell transplant. But lately I have become more concerned with another number, "Absolute Blasts." Blasts are the leukemia cells that would have become neutrophils if I didn't have the nasty mutations in my hematopoietic stem cells.

Here's the basic vocabulary of my particular number-tracking:

**White Cell Count** = the total number of white cells measured in thousands per microliter, or as it appears in my tests results, K/uL. A microliter is 1000th of a milliliter, and thus one millionth of a liter. The normal range for white blood cells is 3.8-10.5 K/uL.

**Absolute Neutrophils** = total number of neutrophils per uL. (For some reason the test results are given in neutrophils per microliter rather than in thousands per microliter -- K/uL -- as in the white cell count). The normal range is 1,700-7,500 per uL.

**Absolute Blasts** = total number of blasts per uL. Normal level = 0.

**Hemoglobin** = the weight of hemoglobin in grams per deciliter (10 milliliters). Normal range: 13.6-17.2 g/dL.

OK, that's the vocabulary and measures. Here's my story of numbers over the past 10 days:

August 1: absolute blast number was 284/uL. Nothing to worry about I was told.

August 3: absolute blast number stood at 440/uL. The doctors showed no concern.

August 8: the blasts had risen to 840/uL and my overall white cell count to 16.8, well above the upper limit for normal (10.5). Dr. Williams in Madison, where I had had the blood draw, came to me and showed considerable concern. He asked me what the plan of the Milwaukee team was for a rapidly rising level of blasts. He emphasized to me that the issue was not just the level, but how rapidly it had risen since the August 3rd. I called the Cancer Clinic in Milwaukee and asked what I should do. The doctors there were already looking at the lab results. They called me back and said I should start on Hydroxyurea, a standard chemo to block the production of white blood cells, and with that also knock down the blasts.

August 10: the blasts kept rising, this time to 1220/uL. Now that I was blast conscious this was discouraging, since I had been on Hydroxyurea for two days. I called the cancer clinic. "We're not too concerned," I was told. "Your white count has dropped a bit (from 16.8 to 12.2). We'll be seeing you on Monday and get lab results then and discuss what to do." I put the whole business out of mind over the weekend. All three grandchildren were here and I was immersed in the joy of their presence.

August 13: The blasts were cut in half, down to 600/uL, and my white cells back in normal range. What a relief.

All other numbers were fine.

### **The Monday consultation and testing in Milwaukee.**

All day Monday was spent at the Cancer Clinic in Milwaukee: labs at 8:00 a.m.; meeting with the quality of life social worker at 9; bone marrow biopsy at 10; psychological evaluation at 1:00; and then various CT-Scans at the end of the afternoon.

The bone marrow biopsy was the best ever. I went through my ritual: First a pep rally with my pain receptors in my sacrum. Once again I praised them for the good work over the past 71 years. The spontaneous visual image was quite silly, as it has been in previous visualizations: a big lecture hall (I think, if my memory serves me correctly, room 5240 in the social science building). In the seats were basically bolts of electricity excitedly cheering. So, I expressed my gratitude and reminded them that the procedure which was about to happen was something I wanted so they should back off. They should still do their jobs since that was their nature, but they didn't need to inform me of the danger. Then I visualized the open buzzing spaces within solid bone and how the molecules should just relax a bit and allow the drill to pass through without resistance.

Once the procedure actually began, I focused my breathing and attention on the pressure point where Amber was doing the drilling. My entire attention was on that spot. The image that drifted in my mind was of the narrow path through the jungle with high tightly trimmed hedges (like in a formal French garden) on either side. In previous strolls through the jungle I heard tiger growls. Last time there was even a paw that poked out at one point. This time all was quiet. "We're done", Amber announced. I didn't even notice the moment of extraction of the plug of marrow.

Afterwards I asked Amber to show me the device that she used to extract the marrow. It was kind of like a hand auger drill -- t-shaped with a long hollow metal needle and a sharp cutting bevel at the end. Pretty fearsome to look at. I've attached a picture.

The psychological evaluation was interesting. I like the psychologist a lot. I took a battery of tests. There were only a few questions that I wasn't sure what was the answer that felt right. "Do you almost always put the needs of others ahead of your own?" Well, for certain "others" if the needs in question are pressing I certainly do, but more generally I do give priority to my needs some of the time. There was also a cognitive test. "fish, velvet, church, daisy, red." See, I still remember the five words a day later. One of the tests turned out to be way harder on the spot than I would have imagined: "tell me as many words as you can in one minute that start with F". Now I could give you dozens and dozens. But in the testing room I only came up with 20 or so. Pretty pitiful. still, that was enough for a perfect score. Low bar. Overall I got 30/30 on cognitive ability.

The main point of the psych evaluation was to be sure about my general emotional stability in the context of five days of total isolation in a lead-lined room. They don't want someone in the study who might freak out when they are radioactive. I told the psychologist that of all things in the treatment, I was most excited about the lead-lined room. For me this is more like an adventure than solitary confinement in a prison. Anyway, I said, I look forward to be able to write about it in real time in my blog, assuming that we can get around the no laptop rule. She thought that probably there would be a way to allow me something suitable, since it is hard to figure

out why there would be blanket ban on say a tablet since a cell phone is allowed. I will work this out with the study team once I know the outcome of randomization.

Randomization: that will happen next Monday, August 20th. That is the next juncture in this narrative. I know I will be disappointed if I get randomized into the salvage group, but this shouldn't matter in the longer term since I will still get the IOMAB-B treatment eventually.

The only loose end from the day's many tests is the result from the human-mouse antibodies test. That won't be known for a few days, since the blood has to be sent to a specialty lab somewhere. I can't imagine how actual mouse cells could ever have gotten into my blood, so I'm not worried about this.

## Comments

Being a patient seems to be an awfully complicated business.

—*Dan Hausman, August 14, 2018*

sometimes being a patient is an oxymoron....

—*Beth Wright, August 14, 2018*

I stopped peeling carrots for the kids after reading one of your posts. My grandma, like your mother, believed the vitamins were in the skin and didn't like them peeled. Hugs

—*SARAH S, August 14, 2018*

I loved reading your visualizations! As I think you know, I am cheering for you every day. Love Cindy

—*Cindy Costello, August 15, 2018*

Just to say that I have been following this really gripping account.

You are my favorite Neutrophil and I think of you whenever the Absolute Blasts start getting to me via Fox News and Twitter.

So glad you finished How to be an Anticapitalist.

Also, I want to say that I am very happy that I met Beatrice, and I loved your brief bio of her. I did read Trevor Noah's *Born a Crime* on your recommendation and it was great; gave a copy to a good friend who was in the hospital most of July, to good effect.

Best to you and Marcia,  
Nancy

—Nancy Folbre, August 18, 2018

## Waiting to be Randomized

August 18, 2018

On Monday the 20th I will be randomized in the clinical trial. Strange expression: "I will be randomized." For a while I thought that this was the first occasion in which I was subjected to this verb. But if being randomized means being randomly assigned to one group or another, then there was one other momentous moment of my randomization: the draft lottery for the Vietnam War.

To avoid being drafted in 1968, I enrolled in a Unitarian Seminary which enabled me to get a 4D deferment. I then got a scholarship to study at Balliol College, Oxford, so I worked out an arrangement with the seminary to stay enrolled there while studying abroad. At Oxford I did a second B.A., this time in history, and I made a point of having as many as possible of the ten "papers" (i.e. topics of study in Oxfordese) have something to do with religion: one on the Crusades, and two on the Puritan Revolution in England.

After finishing my degree in June 1970, I returned to the US and entered the Starr King School for the Ministry in Berkeley. 1970 was also the first year of the draft lottery. As I recall, birth dates, written on slips of paper, were placed in capsules, put in a large glass jar, and then randomly picked. February 9 was 338. In 1970 only dates up to 195 were drafted. So, I dropped my deferment, became 1A -- eligible for the draft -- and applied to graduate school in Sociology at Berkeley.

So, I guess this is the second time I have been randomized. Idle musings.

The best event of these past few days has been a massage by my daughter Jenny. Jenny went to massage therapy school in Arizona after she graduated from college. In our storage space on the third floor we have kept the beautiful portable massage table Marcia's sister Janet gave her as a graduation present. So I asked Jenny if she would give me a massage, and she enthusiastically said yes. It was wonderful. She seems to have remembered everything she learned in her training. The massage was as good as any I have ever had, but it had the added sweetness of coming from my daughter.

## Comments

Draft lottery was only pseudo random -last in first out when mixed in the barrel. Don was born in December and was #42. So the lottery where you were truly randomized was birth!

—Myra Ferree, August 18, 2018

## A fantasy, an op-ed, my video ASA talk & my state of mind

August 19, 2018

### A Dream

Last night I had a delightful dream. I mostly knew I was dreaming, although like in many dreams there were moments when the dream seemed real enough. I was enjoying the dream so much, and wanted to be sure that I remembered it, that in the dream I said to myself, "let's go over this again." Here is the dream pretty much just as it wafted through my sleeping mind:

A Giant Rabbit came up to me and whispered in my ear, "Tomorrow when you wake up everyone on earth who has acute myleoid leukemia will be completely cured." This got my attention. I smiled broadly. I never really saw the Giant Rabbit, only its shadow. "But," the Giant Rabbit continued, "I'm not God. I could never have been able to cure everyone of acute myeloid leukemia if all of the human scientists hadn't discovered the underlying mechanisms of the disease. I can't do research because I don't have opposable thumbs. But once I had that knowledge from humans, then I could cure everyone."

I said, "But if everyone with acute myleoid leukemia wakes up completely cured, everyone will assume that this must be because of God."

"No no no," said the Giant Rabbit. "I'm just a Giant Rabbit. You have to blog about this first thing in the morning so people will know that the cure couldn't have happened without good research. I didn't know anything about leukemia until the research was done."

Laughing in my sleep, knowing that this was all a lovely fantasy, I told the Giant Rabbit I would blog about this right away.

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### An Op-Ed

A week or so ago in a period of good energy, I wrote an op-ed which I will send to the NYT, on a voting system that would make Gerrymandering pointless. I had been thinking about the ideas in the piece for a long time -- since working on the book, *Legislature by Lot*, with John Gastil last year. For some reason, I suddenly felt the

urge to write a very compact statement of the central idea. I am sure the NYT won't publish it -- it is not really written in proper op-edish style -- but I wanted to write it anyway. So, here it is so at least those of you who are interested can see what I have to say:

## **How to make Gerrymandering Irrelevant**

Every electoral system faces the problem of how to translate the principle of political equality among citizens into the actual distribution of power within elected legislative assemblies. The simple formula for expressing this ideal of political equality is one-person-one-vote. In a direct democracy, where citizens gather in a town hall meeting to discuss and vote on matters of municipal policy, this is not so much of an issue. But once elected representatives are the actual makers of legislative decisions, things become complicated since there are many ways to undermine the one-person-one-vote principle in translating citizen equality into legislative power. One of these problems is Gerrymandering, the practice of a political party drawing the boundaries of electoral districts in such a way as to concentrate as many voters of the opposing party as possible into as few districts as possible, and to create other districts where the party drawing the boundaries has a significant, but moderate majority. This results in a much weaker ability of voters in the opposition party to translate their voting strength in the electorate into voting power in the legislature.

There are many proposals for reducing the negative effects of district boundaries on the principle of democratic equality. All of these proposals share one common feature: they assume that voting by elected officials within legislatures should work on a one-person-one-vote principle, mirroring the elections through which the legislators themselves were chosen. But let's imagine a different system for assigning the voting power of each elected official in a legislative assembly. In every electoral district, every candidate who receives above some threshold percentage of the vote gets elected. If the threshold is set at 25%, for example, then then this would mean that a maximum of three candidates would be elected (since it is impossible that four candidates could each get precisely 25% of the vote.) The threshold could be set much lower of course, allowing more candidates to get elected, but then electoral districts would need to be larger to keep the number of elected legislators at a reasonable level. In the election, voters would rank-order their preferences for candidates on the ballot, so the second preference of voters for candidates who didn't cross the threshold would then be distributed to the successful candidates.

Now here's the critical idea: when these now-elected legislators cast their votes in the assembly, *they cast the total number of votes they received in the election* – the sum of the first-place votes they received plus the votes they received from the distribution of votes from the losing candidates. For example, suppose in an election with 1 million votes cast, three candidates in a field of six cleared the threshold of 25%. After distributing the votes from the candidates below the threshold, the total votes for the top candidate was 400,000 votes; for the second 350,000 votes, and for the third, 250,000 votes. When a piece of legislation was subsequently voted on in the legislature, these would be the number of votes each of these elected legislators would cast. Before the digital age, such a system would have made counting votes within legislatures extremely cumbersome. With contemporary computer technologies, it would be a simple matter to tally the votes.

Let us call this proposed system the *citizen-direct-representation* voting system. Each citizen decides in the ballot box which political party or independent candidate will be given his or her vote to cast in decisions over legislation.

The implications of this shift in translating the votes of citizens into the voting power of elected officials are substantial. In terms of issues currently in play in American politics, gerrymandering the boundaries of electoral districts becomes pointless. In the proposed alternative, the effect of drawing a district boundary with a high concentration of voters of one particular party would only be to create an individual elected official with enormous voting power within the legislature. Regardless of how district boundaries were drawn, if in a state 53% of the voters preferred a particular party, then 53% of the votes cast within the legislature would come from legislators of that party.

But there are even more important implications. First, and most profoundly, a citizen-direct-representation voting system changes the relationship between citizens and their representatives. Citizens would now plainly see that when they cast a vote they are actually choosing someone to represent them in the state. For the first time the expression “every vote counts” could be taken literally: every vote will be reflected in the relative voting power of elected officials within the state. Even if you are in a district in which only 30% of voters share your political preference, your vote will be translated into legislative influence. There are no wasted votes in elections. This should significantly reduce voter alienation.

Second, a citizen-direct-representation voting system will make it easier for new parties to form and gain political traction. If the threshold for getting elected were set at 25% to allow for three elected representatives, then almost certainly over time stable third parties would emerge. But even in the most restrictive design in which the threshold was set to limit elected representatives to two per district, third parties would play a more important role than in winner-take-all elections. Third parties could no longer be “spoilers”, by depriving a major party of the needed votes to win an election, but the weight of the voters for a third party would be registered in those voters second preferences.

Third, a citizen-direct-representation voting system is likely to reduce the significance of unconstrained private money in elections from corporations and wealthy individuals. In a winner-take-all election, it is worth spending a lot of money to change the distribution of votes in swing districts between two parties by a few percentage points. That can make a big difference in the outcome of an election. But in a citizen-direct-representation system, the candidate who would otherwise have lost the election and thus have no power in the legislature would still be elected, just with fewer votes to cast. The political returns for electoral spending by wealthy individuals and organizations would be reduced.

Citizen-direct-representation voting is not currently on the political agenda of any of the reform efforts of the American electoral system. It should be.

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## My Talk at the American Sociological Association



I was on the program at the ASA in early August to present some of the core ideas in my forthcoming book, *How to be an Anti-Capitalist in the 21st Century*, but of course because of my illness I was unable to attend. Instead, in July my graduate student Pete Ramand made a video recording of the presentation I would have given. This was the shown during the session at the ASA. I have uploaded it to YouTube and attached the link below.

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## My state of mind

As I think must be obvious if you've read this far, I am full of energy and enthusiasm today. I got two units of lively red blood cells on Friday, and have finally figured out a strategy which I think knocks out my persisting night time coughing. Up until three nights I ago I had been taking the three medicines used to quell the cough -- a children's cough suppressant (Delsym), Teslan Perls, and Benadryl -- sequentially, spread out over a couple of hours. Three nights ago I took them all at once. It worked. So now I am getting much better sleep, even though I still have to change t-shirts 4-8 times a night because of night sweats.

By the end of today, I think I will have everything on my to-do list cleared once again: the final letter of reference for the coming season done and uploaded. It still feels strange to me not to have several manuscripts of different sorts in active preparation, travels plans to nail down, lectures to prepare, papers to review for various journals. The only part of this that I do miss is being actively working on some academic writing project, but this blog has beautifully filled that need. I suppose the urge to write the NYT OP-ED came from that space as well

Tomorrow is Randomization Day. It will be nice to have the course of action set, whichever arm of the study I end up on. I'm not anxious about this.

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## Comments

I really like the juxtaposition of the Giant Rabbit story and the op-ed. Two somewhat different forms of writing (to say the least) but together showing your amazing mental energy awake or asleep. I haven't heard before this sort of electoral proposal discussed. It makes sense to me. I really like the combination of preferential balloting - already a reality - with multiple-representative districts. Do you know of anyplace where a system like this is in practice? It really would solve a lot of problems, although it's complicated!

—Mary Jo Maynes, August 19, 2018

"I can't do research because I don't have opposable thumbs." How many times have I heard THAT excuse?



Sheesh.

—John Gastil, August 19, 2018

And Happy Randomization Day!

—John Gastil, August 19, 2018

Dear Erik,

I read about this when coming back from my holidays and jumped on Caring Bridge to see your updates. It was nice to read your beautiful words and to see all your energy. I also left the pile of emails in my inbox aside, opened your video, instead, and started to take notes, giving the working week a much more meaningful start. My very best wishes for now

Lots of love from Italy,  
Andrea

—Andrea Felicetti, August 20, 2018

Sending great randomization vibes! Good to know a new direction!

—Josh Wright, August 20, 2018

Hi there Erik -

It was a struggle for them to get your video audible at ASA, but after a few minutes, they made it a go. I sat next to Matt Vidal for your talk, and after the session we recalled a discussion with you back in "the day" (our "day," of course) about rupture, revolution, and the relationship between revolutionary movements and interstitial reforms. I look forward to seeing your book and wish you good news in your search for an effective treatment, and in short order. I've sent your posts on to a close friend who is undergoing a similar trial treatment (so far to great (and unexpected) success), and appreciate your courageously sharing your experiences, thoughts, and hardships through this time.

Amanda McMillan Lequieu happens to be one of my office mates right now. She forwarded me your announcement. Pam Oliver filled me in about your journal. There are more of us talking and thinking about you than you might know, and we're all pulling for you.

Regards - Ben

—Ben Manski, August 30, 2018

## 2-3 day delay in Randomization

*August 20, 2018*

**Flash news from Milwaukee. August 20, 3:20 p.m.** Because of paperwork that has not yet been signed, the Randomization to the treatment or salvage arm of the clinical trial has been delayed. According to The Powers That Be, Randomization can only occur when the clinical director at the donor site signs off on the paperwork certifying that the stem cell donor is healthy. The study team in Milwaukee has already had telephone confirmation of this, but the study protocol requires official signatures on official paperwork. That will be done by Wednesday or Thursday of this week. Thus the delay. Limbo continues. By all reports, Erik remains calm and serene in the face of ambiguity. What will be will be, he has been heard to say. As soon as a resolution of this ambiguity occurs, the news will be posted at this site. Be well and in good spirits.

## Comments

Calmly but with resolve, waiting with you and with so many of your friends, standing by your side.

*—Isabelle F., August 20, 2018*

Waiting with you, dear Erik! Your inspiration is eternal! sending you a big hug and much love -

*—Masoud Movahed, August 20, 2018*

Drat.

*—Jody Whelden, August 20, 2018*

We wait, every day. You are our beacon of light! With so much love.

*—Magali Larson, August 21, 2018*

## More thoughts on writing about my emotional state

*August 21, 2018*

Heisenberg famously showed that the very act of observing a particle affects the particle. This is obviously also true about "observing" one's emotions rather than just "having" emotions. The matter gets even more complicated when one analyzes one's emotions, writes about them, and then shares what one has written with others. This, of course, is what I am doing in my posts. And things get even more interesting since some of the wonderful people who read my postings comment on what I have to say and I, of course, read the comments. All of this creates a tangled process of feedback and awareness and reflexivity that unquestionably affects how I feel.

In such a complex process it is a bit elusive to ask "what do I really feel?" One thing I know for sure (as I said in early posting on these issues in April) I never "put on a happy face" in the sense of communicating contentment when I am actually feeling miserable. I don't think I ever am "inauthentic" in that sense. But I also know that I am positively affected by so many people having said how much they admire my general equanimity, so my peacefulness about all the uncertainty of the moment and the dire possibilities that lie ahead is at least in part a result of my experience of sharing my feelings and therefore becoming embedded in something that is a collective experience and understanding with all of you.

But you should all also know this: when I am not reflecting and analyzing and writing, there are moments when I do feel waves of foreboding. I can be sitting with Marcia, alone together, and emotions well up. Sometimes these are fullness with love of life, and grandchildren, and connection; sometimes of grief and a sense of bleak unreality. All of that is happening also.

## Comments

We are with you when you are sad and scared, too. You don't have to act happy all the time, and I think you know that. At the same time, writing (or talking) yourself into a more tranquil state isn't deceitful, either. They are both true all the time. Life is about this intertwining of horror and joy. All we can do is be alive to it all. In that sense, you are a great example to us all.

—Pamela Oliver, August 21, 2018

So agree with Pamela Oliver...you are an incredible example to us all Eriki! And one of the MOST important pieces of this last post is one sentence that contained the word 'Marcia'. Talk about your rock! I know it's often overwhelming and scary for you both but the beautiful news is that are a 'both'. So so lucky for you! in the midst of some damn un-lucky stuff going on.

—Kathy Cole-Kelly, August 21, 2018

Ditto to the above! (We are sometimes reading other commentators' comments as well as your posts!) And also am noting that when we your readers, commentators etc. some days just click on the heart, it's of course a simple keystroke, but it also means we are "feeling" something. But what? how is it related to a "real" expression of emotion?

—*Mary Jo Maynes, August 21, 2018*

Very deep. I want to post a comment but can't find the words.  
xo

—*Sarah Siskind, August 21, 2018*

You certainly bring us with you on this journey.

In my book, you are being courageous.

As well as being cured.

Much love from the Left Cosst family.

—*Martin Goldstein, August 21, 2018*

## Delays but not a derailment

*August 23, 2018*

The randomization has been delayed. It seems that the wonderful 31 year old American woman who is a perfect match and has confirmed her willingness to donate has a "clearable" medical condition which prevents her from donating right now. This is usually, I was told, an infection of some sort, and often is resolved in a relatively short time (whatever that means). But until she is completely over whatever ails her, she cannot donate her stem cells. So, I am on hold.

In the conversation, I got more information on what is involved in the donation process. Apparently for the study, the donation is not of stem cells in the peripheral blood as I had thought, but actually of bone marrow, which requires the donor to be under general anesthetic. That is obviously a much bigger commitment than a typical stem cell donation. Originally, I am now told, I had two confirmed perfect match donors from the 27 million person donor registration (I had thought it was 3), but only one of these was willing to have a bone marrow extraction, which reduced the effective donors for participation in the study to one. This person should still be eventually available, but with a delay of unspecified duration.

Just after the initial call with the disappointing news, I got a second call from Dr. Hari, the head of the transplant team with two new pieces of information. First, they have identified another perfect match, who they will be contacting immediately. And secondly, the institution that is organizing the overall study told Dr. Hari

that he could, if needed, use stem cells in the peripheral blood rather than a bone marrow extraction, which may mean that the second original perfect match donor might now be available. I asked if there was a disadvantage with using stems cells in the peripheral blood and was told that this can make the host-graft disease problem a little more difficult to handle. "But don't worry about this," Dr. Hari said, "we can easily handle that."

My current blood counts on the various dimensions that matter -- red cells, platelets, white cells, blasts -- are acceptable and fairly stable over the past week, so things still seem on track for ultimately favorable outcomes. I'm not on the verge of everything unraveling. I feel good, with what I might call wistful fatigue rather than debilitating exhaustion. Monday I will go to Milwaukee for a consultation with both the hematology oncology team and transplant team. They will tell me what the holding-pattern strategy will be while we wait for the donor situation to get settled. So it goes.

## Comments

Sounds excellent, though crazeeee. Thanks for the update.

—Sarah Siskind, August 23, 2018

I, too, admire your equanimity.

—Sarah Siskind, August 23, 2018

"Wistful fatigue" is another condition I'll now add to my vocabulary. I think I've experienced that, under different circumstances obviously.

—John Gastil, August 24, 2018

## A New Writing Project

August 25, 2018

This is a slow news day: I'm still in limbo and won't have any new information until Monday, August 27th. I'm feeling fine -- my hemoglobin is holding its own, I'm sleeping well, and my taste buds even seem to be returning to something sensible. Last night Marcia and Judy made me sweet and sour stuffed cabbage, one of my very favorite dishes (I always order it on my birthday). I wasn't sure how my errant taste buds would react, but to my great relief, it was delicious. I ate six of them, probably more than I have ever eaten in one sitting.

I have decided on a new writing project besides this journal. I am writing a long meandering letter to my grandchildren, Safira, Vernon and Ida. I will write about my childhood, about raising their mothers, about my work and ideas, my values, politics, and many other things. If I live through this illness, then this will be a nice thing for me to give them when they are old enough to understand it. If I don't, well then Jenny and Becky can read it to them so they will know more about me.

I decided that this is really something from me to the three of them, so I won't include the letter in my postings. But when there are specific passages that I especially like and want to share, I will. I've just finished a long section which I labeled "The Big Picture: how I think about life". It wanders over all sorts of themes, from cosmology to religion to values to the idea of "the meaning of life." I thought I would share the opening few paragraphs:

**An excerpt from "A letter from Dadoo to my wonderful grandchildren"**

We're alive. That's a pretty amazing thing, really. But here is something else: we're not just alive, we are *aware* that we're alive, we know we're alive. Trees are alive, to be sure. But trees don't think about being alive. Ducks are alive and do all sorts of wonderful ducky things, like flying in the sky and making ducklings. But ducks don't sit back and think about being ducks: "Wow, I'm a duck! What is my purpose in life? Why am I here? Am I happy?" No, duck's minds don't do that. Our's do. We have minds of a very special sort – minds that think about the world, about our own lives, and what may seem even stranger, minds that think about our minds. That is really something: a mind that is self-aware of itself. Shut your eyes. Take a deep breath. And think about the fact that you are thinking.

Now, here – to me – is the really astounding thing: we are made up of the same stuff as rocks and trees and stars and ducks. We are made up of matter – atoms of all sorts of elements: carbon, oxygen, iron, hydrogen, altogether somewhere around 100 different kinds of elements. Those elements combine into a fantastic array of different kinds of molecules. And then those molecules get connected in all sorts of incredible ways to make up all of the organs of our bodies, including our brains. And somehow, mysteriously to me, our brains produce our minds. Our brains are physical things, made up of nothing other than atoms and molecules, just like everything else. And yet this brain stuff is organized in such a complex way that out of this purely material, physical organ, a mind emerges. A mind that can think about brains. Here's a fancy of saying this: We are matter made conscious.

Here's another thought about our minds: our minds are capable of being creative, of producing ideas that have never existed before we thought them. Ideas are not physical things: they are produced by our minds which are themselves produced by our brains which are physical things. This is weird, strange. Mind-boggling as people say. But there's more: Our wonderful weird minds don't just produce ideas about things we see in the world. I see a cow, and then I have the idea of a cow in my mind. That's pretty cool. But how about this: I can create the idea of a cow that speaks French and rides a motorcycle, and then I can draw a picture of that cow and tell a story about how it fell in love with a duck named Cherry from Kalamazoo and then how they had children who were half duck and half cow.

And there's even more: what about music? Our minds create music out of nothing. Well, almost nothing. We

hear birds chirping and describe some as “song birds,” and the beating of our hearts are kind of like drums, but basically music is something our minds create. Glorious Beethoven symphonies and string quartets (my favorites); pounding rock music; lyrical rap music; blues, jazz, samba, reggae, waltzes, polkas. Sounds of all sorts combine in our imagination by our minds and then are turned into something physical – sound waves – which we hear. When I think about this, I am filled with wonder.

## Comments

This letter is wonderful, dear Erik! I am very happy to hear that you feel better and able to sleep! Sending you big hugs and much love -

—*Masoud Movahed, August 25, 2018*

Dear Erik, I love the beginning paragraphs from your letter to your grandchildren. Please share more as you write....Yes the wonder of it all. Sending love, Cindy

—*Cindy Costello, August 28, 2018*

## Medical Update: some more definitive news

*August 27, 2018*

I now know for sure what the immediate timeline is. There are two possibilities: (1) If a donor is cleared by Friday — either the donor with the “cleanable condition” or the back-up donor — then I will be randomized in the clinical trial. There is a third, new donor, in the wings, but that donor would take more time to work up and get cleared. (2) If no donor is cleared by Friday, then I will be hospitalized in Milwaukee over the weekend to begin a new round of chemotherapy, using the CLAG-M cocktail, in the hope of producing a complete remission. This will mean 28 days in the hospital ending with a bone marrow biopsy to check the level of remission. If I have a complete remission (which is unlikely), then I go to transplant; if I am still refractory, then at that point I re-enter the clinical trial for Iomab-B. Presumably by then one of the donors would have been fully cleared (i.e. healthy). Once again, of course, re-entering the trial means getting randomized which means I could end up in the salvage group and get one more round of chemo attempting to produce a complete remission before actually getting the Iomab-B treatment. Sigh.

The reason for #2 above is that Dr. Michaelis did not want me to stay in my current holding pattern for longer than another week. My blasts have been rising, and while things are not out of control, she felt it important to return to a more active treatment of the disease. Thus, CLAG-M lurks on the horizon. This concoction is

supposedly a bit more aggressive than anything I have had so far, but still should be something I should tolerate well without misery-inducing side effects.

Dr. Hari, the head of the transplant team, ducked in briefly during the consultation. He assured me that whatever the delays were, the study would remain open and my slot was assured. We just need a bit of luck this week to get on with it.

So, if a donor gets cleared, then we are back to the previous scheduled delayed by a week. If a donor is not cleared, then everything will be dragged out another 5-6 weeks, with the earliest possible date for a transplant being well into October. I'm not especially upset about this. I don't think that these twists and turns will affect the ultimate outcome, and that really is all that matters.

I asked Dr. Hari and the others whether it might be possible to get more information about the medical condition of donor with the "clearable condition." He said that it was absolutely impossible to get any information. The donor registration system creates a complete impermeable barrier between the recipient centers and the donor centers. This is to prevent any possibility of pressure from anyone — rich, power, well-networked people can't interfere with the process. This is all for the good, even if not having better information is frustrating.

## Comments

Thank you for the updating, Erik. All the best wishes from all your friends in Florence. D

*—Donatella Della Porta, August 27, 2018*

## An unexpectedly emotionally intense moment

*August 27, 2018*

Marcia and I pulled into the parking lot at the Froedtert Cancer Care Center this morning. As we usually do, we then talked about questions we would ask. Since there has been uncertainty about the perfect match donor with a "clearable condition", Marcia said, "I want to ask if you would still be eligible for the clinical trial if you only had an imperfect match." When she said this, I instantly felt a wave of panic and started crying. No build up, just tears flowing and a bodily feeling of anxiety that I really haven't felt about my situation. It passed fairly quickly. I collected myself and thought about what had happened.

Here is what I think: Very early on in this process, perhaps the second week of April, I got a call from the stem



cell transplant coordinator saying that three perfect matches had been found. (It turned out actually to be only two, although now it is back up to three). We were thrilled. We were also very impressed that the coordinator would let us know so quickly. From that point on whenever I talked about my illness I would talk about the incredible fact that there were 27 million people who had signed up to the international stem cell donor registry and out of those 27 million, three (i.e. two) were a perfect match on 8 DNA immunological markers. I always verbally expressed my gratitude as a public affirmation for the universal connection, compassion, kindness this reflected. I also think this part of the puzzle of what it will take to save my life has been a kind of anchor for my general optimism. There are so many uncertainties, but this bit is as good as it can be; I don't have to think about it. So, the idea of a Perfect Match had become extremely salient to me emotionally. Marcia's question was somehow experienced by me as a terrible threat, and triggered emotional outpouring. She had no way of knowing that I would react this way; neither did I.

Now, as I write about this, it is all straightforward, unencumbered. A question is just a question. It doesn't change anything. I can write about this calmly. No big deal. But in the parking lot at 9:30 this morning, the same words brought panic and darkness.

## Comments

Sending you big hugs and much love, dear Erik! My thoughts and my heart are with you!

—Masoud Movahed, August 27, 2018

Thanks for telling us about this, Eric!

Yes ... the immensity of it all.

There have been a lot of articles recently in MN about bone marrow transplants because, apparently, it's the 50th anniversary of the first successful transplant here! Some discussion of the donation process too.

—Mary Jo Maynes, August 27, 2018

Such a touching post. Made me realize how important it is to be a stem cell donor. Wish you much love and strength Erik!

—Kerem Morgul, August 28, 2018

Big hug, Erik.

—Joshua Cohen, September 2, 2018

## pre-update posting

*August 31, 2018*

I got a call this morning from the coordinator of the stem cell transplant unit in Milwaukee. She said that they do yet know if the donor has been cleared (i.e. passed all of the medical tests). What they do know is that the tests were conducted on Wednesday, that it normally takes 48 hours to get complete results, and that the donor registration center understands the urgency of the timing so they would try to have the paperwork signed by the end of today. So, everything is still in play, but by the end of the day I should know what lies ahead for the next period.

In April, when I began this blog, I had an early post that played around with the military metaphor for the treatments for cancer, and referred to a particular moment as the "first skirmish". Later I wasn't so happy with the military metaphor -- the battle against cancer, etc. -- even though it continued to resonate. Well, this waiting period, once again, evokes a military metaphor: I have finished basic training and am now waiting for my orders for deployment. Where will I be deployed? Will it be to CLAG-M for another try at robust remission? Will it be into the new, high tech war zone with highly targeted nuclear attacks on stem cells? I'm waiting.

## Comments

fingers crossed !!

*—Mary Jo Maynes, August 31, 2018*

Waiting with you, dear Erik! Sending you big hugs and much love!!

*—Masoud Movahed, August 31, 2018*

Also waiting with you and Marcia and sending much love...

*—Cathy Loeb, August 31, 2018*

Military metaphors are problematic but awfully apt. Hope you're lucky in where you get deployed.

*—Myra Ferree, August 31, 2018*

Ugh, the waiting game. At least you know 1) this round of it has a finite period and 2) some kind of resolution lies around the corner. Sending all my love and wishes for a positive step forward in a new direction by the end of the day!

*—Josh Wright, August 31, 2018*

sending warm thoughts to you both - Beth and Woody

—Beth Wright, August 31, 2018

## Bound for CLAG-M in Milwaukee

August 31, 2018

I just spoke with the head of the Hematology Oncology Team. The donor did not clear, alas, and Dr. Michaelis feels that we should no longer stay in a holding pattern without directly treating the disease. So, tomorrow I will return to the Center for Advanced Care, CFAC, at the Froedtert Hospital in Milwaukee, where a full-scale attack on my refractory acute myleoid leukemia will begin. A new PICC line will be installed (so at least no more regular pokes for blood draws), and I will get the first infusion sometime tomorrow. This chemo will not be slow release like the first round of hospitalization chemo was in April, so it will be somewhat more intense, but it is still not supposed to be dreadful. I will be hospitalized for 2-3 weeks, then return to Madison for another interregnum waiting for the randomization into the clinical trial.

I'm glad we're now doing something and don't feel dreadfully disappointed about the yet again delay in Randomization. I'm finding that it is possible in a situation like this to really prefer X over Y without symmetrically being really disappointed if one gets Y instead of X. This is just the way my story is going. I almost said "the way my story is *unfolding*," but that would have suggested a destiny already existing in advance, a teleological disease rather than story being created as it happens.

In recent days I have begun to feel some symptoms which seem to be symptoms not of treatments, but of the leukemia itself. My hemoglobin remains above the transfusion threshold, but I have increasing fatigue. And I have some abdominal pain on my left side, where my spleen is located, and organ that is often directly affected by blasts. So it goes. The manifest disease itself will now itself be treated fairly aggressively; I will get back to a better equilibrium, and then we will move forward to the transplant. Everyone assures me that there is no uncertainty about that.

As far as I know, I will still be visitable in Froedtert hospital just as I was in April, although I don't really know what physical state I will be in so anyone who wants to come should for sure call in advance. My spirits remain good, but they are occasionally punctuated by thoughts of grim possibilities. I am feeling so much joy and contentment from so many things these days, that even though these positive emotions coexist with dark thoughts about dying, it isn't really the case that the positive is undermined by the negative. They just coexist. They each are what they are; they don't sum up into some simple "net" feeling.

## Comments

“It isn't really the case that the positive is undermined by the negative. They just coexist. They each are what they are; they don't sum up into some simple "net" feeling.”

This is one of the most beautiful— and true— things I've ever heard.

Sending you so much love.

Devah

*—Devah Pager, August 31, 2018*

You just have to keep going one step at a time. Keep your spirits up as much as you can. And just take each day as it comes. Thinking of you and Marcia and hoping this next round of treatment is not too debilitating. Much love and healing thoughts coming your way from us.

Xxxx

*—Janeen Baxter, August 31, 2018*

## mini-update

*September 1, 2018*

We are now ensconced in 7CFAC14, a room much like the one in April. We probably will be moved to a room on the 8th floor once one is available, since we know the staff on that floor so well and they know us, but if not, this is perfectly fine. I'm very relieved to be here. Life is, once again, beautifully simplified: we live in a single pretty spacious room, everything is taken care of for us. Later today I will get a new PICC line and then, in due course, the new round of chemo will begin.

## Comments

You're amazing! I'd be (futilely) screaming in rage, fear, and frustration.

*—Dan Hausman, September 1, 2018*

Simple is good. ??

—Cathy Loeb, September 1, 2018

Erik, I wish you good luck with the new chemo. Your fortitude is beautiful to behold.

—elliott sober, September 1, 2018

Sending a squeeze from NYC! Cheers to simple things!

—Josh Wright, September 2, 2018

## An update & a story

September 2, 2018

### Medical Update

The last sentence of yesterday's posting was this: "Later today I will get a new PICC line." Ha! That seemed like a sound prediction. Indeed it was a good prediction. But "the best laid schemes o' mice an' men and PICC line technicians Gang aft a-gley" ("awry"). Here's the story.

It seems that there are two ways to install a PICC [peripherally inserted central catheter] line. The first way is in an intervention radiology facility where they can do the process with a real-time high resolution image of the path the catheter must travel. That is the procedure I had in April with my previous PICC line. It was pretty painless and took place without a hitch. The IR procedure also makes it possible to insert what they call a bi-flow PICC line which is the kind you can keep for months when you are outpatient. The other way is done bedside, using an ultrasound to guide the process. You can't insert the fancy bi-flow catheter this way for some reason, so the PICC is removed when you are discharged from the hospital.

Well, I arrived on the Saturday afternoon of Labor Day weekend and the IR unit was closed. To do an IR procedure, therefore, would mean delaying the chemo until Tuesday. Dr. Michaelis did not want to wait that long, so the bedside procedure is what needed to be done. Seemed reasonable under the conditions. Alas, the technicians simply couldn't get the needle properly inserted into the vein in my bicep, which is the first step in the procedure. They tried twice. The first time, they said that they couldn't get the needle to penetrate the wall of the vein. Maybe there was scar tissue there. As they described it, as they pushed the needle against the wall, the vein just wiggled around. Although they had given me a local anesthetic of lidocaine at the outset, the more they monkeyed around in my arm trying to get the needle in, the more painful things became. I was doing focused breathing, but I hadn't been prepared for an ordeal, and it certainly didn't do much for the pain. My

breathing became more intense and rapid. I even tried invoking the visualization I used in the bone marrow biopsies to get my pain receptors to back off (see posting on August 14). For a fleeting moment I visualized the classroom where I had given my sacrum pain receptors a pep talk asking them to back off. The room was empty. They were too busy doing their job. In the second try, the technicians got the needle into the vein, at least as indicated by the ultrasound, but they couldn't get any blood back flow. More intense rapid breathing on my part. **Since they saw how distressed I was, they stopped trying and pulled out the needle.** They admitted they didn't know why this was happening.

Marcia was out of the room because the procedure was done under sterile conditions -- they wore masks and gowns and I was shrouded in blue sterile clothlike paper with only the patch on my arm where they were trying to insert the catheter exposed. When Marcia came back in the room, thinking this was all done, they told her that they were unsuccessful. What happens now? They explained that there was a "two poke" rule, so they would have to wait a while and someone else from the IV team could come by. At that point my ferocious guardian told them that she did not want anyone to try again. We talked to the physicians assistant who was on the floor, who agreed that there should not be another attempt at the bedside procedure. She would talk to the rest of the team and try to get Intervention Radiology to do the bio-flow procedure the next day (today, Sunday, August 2). She called at 7:00 in the morning and then told us we were on the docket. At 2pm I was wheeled down the IR and had a lovely bi-flow PICC line installed. While I was being prepped, I chatted with the assistants to the doctor who actually did the procedure and told them what happened. One of them said, "They do an OK job, but they're bush league." Afterwards I thanked everyone for coming in on Sunday to rescue me. The doctor said, "It is the least we can do considering what you are going through."

There was one other night time mini-drama. At around 1:30 another lab tech person came in, this time for a blood draw. Since I didn't yet have a PICC line, this meant a poke. No big deal. I had had a fabulous blood draw right after I arrived by a tech guy who took the blood from the back of my hand. He was so smooth that I really didn't even notice when he poked me. Not so this time. Another case of two failed pokes. The first on the back of my hand, the second near the crook of my arm. In both cases the medical tech somehow stuck me with the needle, wiggled it around a bit hoping to draw blood, but to no avail. No lidocaine this time. I have had dozens of blood draws with needles rather than a PICC line since April. These were the first failed attempts and the first that really hurt. My ferocious guardian spring from her bed. She invoked the two poke rule. I know the rule, the tech mumbled under her breath, embarrassed, I suspect for having failed to get a blood draw from me. The nurse came in and said there would be no more tries that night. The blood draw could wait until after I got a PICC line. He put a big handwritten sign telling anyone from the lab to see the nurse.

Everything is now nicely in place. As I write, the first of two chemo medicines is calmly dripping into my new PICC line. In the end, Dr. Michaelis decided not to do CLAG-M, and instead we are doing a regimen called FLAG. FLAG is close to CLAG, but for some reason the team felt it was better for me in preparation for the clinical trial. This is also why the M was dropped. That was a most toxic component of the original plan, intended once again to attempt a complete robust remission. Dr. Michaelis told me that she did not want to "wreck your body" before the clinical trial, and that was why she was dropping M. I took that as a pretty clear signal that the fundamental plan is to do the clinical trial once donors have cleared. There is no expectation of the robust remission needed for standard transplants.

Here is the routine for this round of chemo: (1) a half hour infusion of pre-meds: a steroid and an anti-nausea medication; (2) 30 minute infusion of Flouarabine, the FL in FLAG; (3) Steroid eye drops to prevent irritation from the chemo; (4) a four hour break; (5) four hour infusion of Cytarabine (which is the A in FLAG since another name of the drug is Ara-C). (6) more steroid eye drops during the chemo drip. All together this takes a total of about 9 hours. We started at 4:30 pm; we'll end around 1:30 or 2. Repeat for five days. (7) Then in the days that follow the chemo, I get daily shots in the abdomen of neupogen, also called G-CSF (and thus the G in FLAG) to stimulate white blood cells to try to restore neutrophils. That is more or less what lies ahead. I'll be here until my neutrophils rebound enough for it to be safe for me to go home, probably three weeks or a bit more.

## A story from my letter to my grandchildren

I am thoroughly enjoying writing my meandering letter to my Grandchildren (described in the post on August 25). There have been days when I was able write for five or six hours, immersed in the task in much the way I can get when in the midst of an academic writing project. It is pretty revealing, I think, that so little time elapsed between my completion of my book and my decision to write the letter to Grandchildren. The Caringbridge blog also fills me need to write, but there are days when there isn't anything to write about for the blog, so I was feeling an itch to do something else. I needed a writing project. When I have the energy for it -- which I seem to mostly have these days -- I find it a much happier way to deal with the large stretches of time I have than binge watching mini-series (although I've done some of that) or reading. And once I got going on this project, I discovered that there were endless things to write about.

As I said in my initial description of this letter, I don't want to post it on line, not because of any feelings of privacy, but because I want Safira, Vernon, and Ida, to really think of this as something special I am writing for them, whether I am around to read it to them when they are old enough, or their parents are my stand-in. Still, I feel fine about sharing pieces now and then which I think many of you will enjoy. Here is one from the section of the letter called *Pranks, Mischief & Shenanigans*.

### *Running away with Connie Baldwin*

The most significant escapade of my childhood in which I broke all sorts of rules was a time when the three of us decided to run away from home with a wonderful friend of ours, Connie Baldwin. Once again, I don't precisely remember the year, but I don't think we could have pulled this off if Woody was under four, and I don't think Colleen would have done this if she was as old as 10. Since we pulled a red wagon for Woody in case he got tired, I think that puts him closer to 4 than 5: by 5 Woody was a pretty robust active kid and I think could have kept up with the rest of us. So, my best guess is that this was in the summer of 1953: Woody was 4, I was 6 and Colleen 8.

Connie Baldwin was my age, but all of us liked her. She was the daughter of a psychology department colleague of my Dad's. Well, in the summer of 1953 her family was moving from Lawrence to Rochester, NY, if I remember correctly. My folks had her family over on a pleasant summer afternoon for a goodbye lunch. The three of us decided that it was unacceptable for Connie to go away, so we decided to run away from home. Colleen was on crutches because she had badly twisted her ankle. She was wearing a poodle skirt, she tells me.

We brought a red wagon for Woody to ride in when he got tired. The parents were talking, and off we went. I don't remember who concocted this idea, but surely Woody would have been too young, so it was either me or Colleen. I suspect that it was me, but that may be unfair to Colleen's sense of adventure.

Now, if you are going to run away from home, you have to have a plan, right? Well, we had a sort of plan. We were going to Mott's Stables just to the west of Lawrence where we had taken riding lessons and we were going to get horses. That was our plan. I have no recollection of what we intended to do after we got the horses. Maybe just improvise.

Mott's stables were almost ten miles away (I just checked). We didn't know that, but we did know how to get there. So we walked, and walked, and walked. Up the hill, across campus, and out to the western edge of the city. We walked for hours, maybe five hours or so. We were getting tired. Woody was in the wagon. We were getting really hungry. It was getting dark. We stopped at a convenience store on the far side of town to buy provisions. My guess was that it was probably five miles from our house. The clerk in the store saw how young we were, how bedraggled, so he asked us where we were going. We told him to Mott Stables to get horses. He told us that there were wolves in the woods outside of town and it would be dangerous for us to try to walk there in the dark. Without too much effort, he got my home phone number from me and called our folks.

As I recall, our Mom, but not our Dad, was really furious at us, and this was the main emotion that greeted us rather than embrace and relief, although those soon followed. We had been gone so long that they had called the police and the police were already looking for us. I can now imagine, as a parent and grandparent, how desperate she must have felt. At the time, when we went home, I think I probably also felt some relief, but I was also really sad that Connie was moving.

## Comments

Love these stories! One of my fond childhood memories was going on car rides and listening to your recollections of "Woody and the Beasts". I also seem to recall made up fairy-tale-ish adventures that you recorded for Becky and Jenny?. Any idea what happened to those recordings? I think they'd be fabulous digitized files for the grandchildren to enjoy!



—Josh Wright, September 3, 2018

Golly - big ambitions even then. Thank goodness for hunger and a wise convenience store adult. Great story.

—Jody Whelden, September 3, 2018

## Nausea and a magic bullet

September 3, 2018

Up until last night, I had not experienced one of the dreadful side-effects of chemotherapy, nausea. Occasional moments of queasiness, but no full-scale nausea. So, I thought, perhaps my system was less vulnerable to this particular form of suffering.

At first last night, during the second phase of the chemo, it seemed that I would have no difficulty. I stayed up rather late writing, given how tired I should have felt. I suspect that the dose of the steroid Dexamethazone, given to me as part of the pre-chemo infusion, was giving me an energy boost. But eventually fatigue triumphed and I feel asleep around 11 p.m. I then woke up around midnight feeling nauseous. In the next hour the intensity got worse. I only vomited once; mostly I was just feeling awful. I could lie down for a few minutes, but then had to sit up to deal with the waves of intense nausea. The nurse consulted with the physician's assistant on the floor, and gave me a dose of Atavan intravenously at around 1 a.m.. Atavan is normally used as an anti-anxiety medicine, but apparently it is also used in cancer treatment to deal with nausea. It was a magic bullet. Within ten minutes all symptoms were muted. Within twenty minutes I was sound asleep. I pretty much slept through the chemo being disconnected, the blood transfusion administered to give me a hemoglobin boost, and the blood draw for labs. I woke up refreshed in the morning, with no shadow of nausea or other side effects.

It is now 3p.m. I've been up since 7, feeling fine the whole time. Before too long I'll begin the pre-meds for the next infusions. But tonight at the first hint of queasiness they'll give me Atavan. I love magic bullets.

## Comments

Sharing your happiness about this magic bullet!

—Cathy Loeb, September 3, 2018

That's fantastic, about the Atavan — Magic Bullet indeed, though you may want to work on that metaphor — a

bit harsh — maybe a soothing blanket of comfort or some such — anyway, anything that protects you from one of the worst side-effects of chemo is gift.

—*Martin Goldstein, September 3, 2018*

This is terrific news, dear Erik! Wishing, wholeheartedly, that this process goes as smoothly as possible! Much love -

—*Masoud Movahed, September 3, 2018*

Glad to hear about the magic bullet!! I've been reading all your posts and thinking about you. I've just started reading Magic Street, which you recommended. I'll have to follow up for the other book as your description was too vague for me to find it.

—*Pamela Oliver, September 3, 2018*

I was going to find the finale on line, as I read your journal. Marcia's video is perfect. Indeed impressive. Thank you!!!!

—*Sarah Siskind, September 4, 2018*

## Smooth sailing

*September 4, 2018*



One of the remarkable features of the disease I have is that there are periods in which I feel 100% healthy, completely free of symptoms, and sometimes even free of fatigue. Tastes of wellness. That is how I feel today. Last night I had no nausea at all from the Chemo. Considering that the first round of the chemo produced such awful, debilitating nausea, I was fully prepared for another onslaught, although this time armed with Atavan, ready to intervene at the earliest sign. But it didn't happen. During the day, yesterday, I started taking Compazine, another anti-nausea medicine. It worked perfectly. So, I had a good night sleep, barely waking up when my chemo ended and my labs were drawn. The lab results show that the chemo has rapidly had its desired effects: my white blood cell count dropped from 16 to 4 (normal range 3.9-11.2) and the percentage of white cells that were blasts from 50% to 3%, and thus the absolute blasts from about 8,000 to 120. That is the pivotal number, indicating the intensity of the presence of the leukemia cells in my system. None of this touches the manufacture of leukemia cells in the marrow, of course. For that we need the transplant. But the active leukemia in my peripheral blood stream has been knocked down very efficiently, which is a relief. This is why I feel so energetic, for the high level of leukemia cells is very taxing. I have been very much "living in the moment", and take things as they come, but is also so nice when the present moment is filled with physical ease.

This feeling of genuine wellness had already started yesterday. In the afternoon I was writing and listening to music from my YouTube classical playlist. One of my favorite pieces came on, Stravinsky's *The Firebird*. I had played this a couple of times in orchestras, from the very back of the viola section. One of the nice things about being in the very back of the viola section is that you are pretty close to the very center of the entire orchestra, with the woodwind section immediately behind you. In the grand moments of the full orchestra playing some

fantastic finale to a great piece of music, this is a wonderful place to be -- completely engulfed in the full power of the music. It is hard to beat the finale of *The Firebird* for this. I stopped writing, turned up the volume on the remote Bluetooth speakers, shut my eyes, and started miming playing my instrument. My bow arm moved with the violin and viola parts (which were pretty much doing the same thing at this point) and my left hand fingering more or less the notes. At some point, when the whole orchestra joined in, I shifted to conducting. The ending of the piece has this wonderfully simple melody of the firebird reborn. It is repeated over and over, sometimes in full, sometimes truncated, sometimes fast, sometimes slow. It is a remarkable ending. I was transported, completely.

Unbeknownst to me, Marcia took a video of the last minute or so of me conducting the symphony playing *the Firebird*. I think it captures something of the joy I was experiencing.

## Comments

Love this! I think you know about the project I've been working on with the Philharmonic... they have digitized many of their scores, and are working on doing all of them. So if you're interested, here's the score to *Firebird*, with Leonard Bernstein's markings:

<https://archives.nyphil.org/index.php/artifact/97e4feef-7f49-42d4-acc8-d2cccffdfc64-0.1?search-type=singleFilter&search-text=l%27oiseau+de+feu&doctype=printedMusic>

You can also find all the parts from that link. This is from a concert he conducted in March 1984. Sadly the original score that Stravinsky conducted from back in the day isn't available yet online... I'll check to see that it definitely exists and what the plans are to release it.

But, nonetheless, this score that you CAN see has something cool about it... Bernstein recorded from this score with Israel Philharmonic. You can find that recording here:

<https://www.amazon.com/Stravinsky-Spring-Firebird-Suite-Bernstein/dp/B000001GDZ>

Fun to listen along and see how the different parts were bowed, how Bernstein marked it up, etc. Maybe an adventure for another day when you're feeling tip top!

Shamus

—Shamus Khan, September 4, 2018

I do not know much about directing an orchestra, unfortunately, but you looked very convincing to me! Baci d

—Donatella Della Porta, September 4, 2018

Wonderful energy and news about the blasts! Speaking of a firebird, it couldn't be more telling!!!!

—Isabelle F., September 4, 2018

So good to have the periods of relief - thanks for sharing your conducting. Jody

—Jody Whelden, September 4, 2018

Nice conducting, Erik!

—elliott sober, September 4, 2018

## An almost perfect day

*September 5, 2018*

It can happen. You can have acute myeloid leukemia, be in a hospital getting chemo-therapy, and have a wonderful day. It helps, of course, that the chemo doesn't seem to be producing nasty side-effects at the moment and that it has been doing its job on my leukemia cells. My only symptom today seems to be occasional hic-ups. I woke up with them at 2 a.m. At that point they brought with them some acid reflux, but Maalox solved that, and the hic-ups themselves didn't keep me awake. So, I slept well and woke up refreshed.

Marcia went to Madison for the day to take care of various matters, so the only downside was being alone. But aside from that, the day was delightful: Occasional visits from doctors and nurses, with friendly chat, good information when asked for, and tender care. Between visits, writing on my letter to the grandchildren. At 11:00 physical therapy class with two other patients, one of whom I had known in April. Ten stations of exercises, just demanding enough to be a bit of a challenge. Then lunch -- Okay, that would not count as delightful, but at least I could eat something -- and then a long afternoon of writing the letter, about 4,000 words today. I am totally loving this. Periodically I give Colleen or Woody a call to check on some childhood memory, and they add details that trigger other memories and ideas. Today, among other things, I wrote about my experience with the boy scouts. I haven't thought about that for many years. My troupe in Lawrence, Kansas, was pretty benign, without a lot of the tough guy militarism and hyper patriotism that characterized lots of scouting. Mostly it was fun. Here is what I wrote:

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I was active in scouting from elementary school when I was in the cub scouts – pack 52—through 7th grade and

then in our year in Australia. I don't think I continued when I returned to Lawrence in the fallof 1961, but perhaps I did for a while. I still remember the Boy Scout "Laws": *A scout is trustworthy, loyal, helpful, friendly, courteous, kind, obedient, cheerful, thrifty, brave, clean, and reverent.* I would still endorse most of those:

- **Trustworthy:** definitely important. When you tell someone you will do something, you should do it. Keeping promises is part of living well with others. And telling the truth (closely connected to trustworthiness) is certainly important, although that is a bit trickier sometimes, since it can conflict with being kind, since you also need to think about hurting the feelings of others. But trustworthiness itself is important.
- **Loyal:** Loyalty is also a little tricky. Being loyal to a friend who has done something wrong and you are asked to lie about it can be a big problem for all sorts of reasons. Loyalty to a person or an organization can often lead people to do things that go against other important principles. So, I would not put loyalty on such a high level of virtue without qualifications.
- **Helpful:** This is definitely a virtue. Helping others in a consistent way is a wonderful way to live. It always makes me happy to be of help.
- **Friendly:** High on my personal list: Being warm and friendly to nearly everyone, and at least civil to people one doesn't like. Being friendly also means not excluding someone from any activity because they may be a little weird or different unless, perhaps, they are super disruptive. There are very shy persons who sometimes feel very excluded because no one is drawn to them. Being friendly means making an effort to include such a person in activities. This can be hard at certain ages, when kids feel that they want to hang out with the cool kids, the popular kids. It is especially important for kids who are popular in this sense to be friendly towards kids who seem left out.
- **Courteous:** I am a big fan of being polite, of acting in a calm and courteous way even with people you don't like. Mostly it makes life go better.
- **Kind:** This is a very big deal virtue. I might even put it at the top of the list. Being kind to people directly makes the world a better place. And putting the personal virtue of kindness at the top of the list might also suggest the importance of making the world a place where kindness among people prevails. That, in a way, what my sociological work is all about: how to make the world a place of kindness and love. But even here there are complications. Bertold Brecht, the great German poet and playwright of the middle third of the twentieth century, was a committed socialist, wanting to help make a world where kindness prevailed, but felt that sometimes this required action that was itself violent and harsh. He wrote in a famous poem: "Alas, we Who wished to lay the foundations of kindness could not ourselves be kind." And the poem ends, with a plea to the future, "But you, when at last it comes to pass that man can help his fellow man, do not judge us Too harshly."
- **Obedient:** No way would I include this as an automatic virtue. Sure, it is fine to obey sensible instructions, and sometimes one needs to obey someone in authority even when they tell you to do something you feel is stupid. But obedience often runs up against doing the moral thing, and blind obedience can be terribly destructive. Sometimes disobedience is what is needed. So, I would kick obedience off the list entirely.

It is way to simple-minded to put kindness and obedience on the same level.

- **Thrifty:** Pretty good virtue. Wasting money is a bad idea. Living beyond what you can afford is a bad idea. Buying less expensive things of good quality is better than getting suckered into buying something more expensive just because of the classy brand named. But don't confuse thriftiness with stinginess. Generosity is a huge virtue, closely connected to kindness. It is one thing to be thrifty in making choices about how to spend one's resources on oneself, but this does not mean withholding resources from others when this shows kindness and consideration. When I go out to dinner with a group of students, I either pick up the tab or, I pass around a hat and tell the students to put in whatever they want to, and I pay the rest of the bill. I have much more money then they do, and this kind of generosity makes their lives go easier.
- **Brave:** Yes, bravery is important. It often takes courage to do the right thing. And it can take courage just to do things you really want to do well – like be in a play as an actor on stage, or perform in a recital, or give a public lecture. Bravery means overcoming fears, and often when one is in a situation that triggers fear, the level of fear is greatly exaggerated. So bravery is a virtue.
- **Clean:** This one just seems weird to me. It comes, I think, from the old Puritan saying, "Cleanliness is next to Godliness." Sure, it is fine to keep your body clean and your room tidy. But messiness is no big deal until it really interferes with life, and often a preoccupation with cleanliness can interfere with doing things that generate mess. So, like many virtues, cleanliness in moderation, within a dose of messiness is best.
- **Reverent:** This is definitely part of the connection between scouting and Christianity. I think reverence, if this specifically refers to revering God, is NOT a virtue. Being respectful of other people's beliefs, that's fine. But reverence as a general virtue is pretty dubious.

And the Boy Scout motto: "Be prepared". I supposed that is pretty good. Be prepared to do what is right. That is better than "Be unprepared."

I was last a Boy Scout at age 14, over half a century ago. Remembering those slogans gave me a chance to sneak in Dadoo Advice in my comments. But those virtues were not what I liked about the scouts. Scouting was fun! We did all sorts of wonderful activities. I learned to tie all sorts of knots, most – but not all – of which I have forgotten. We played games together. Sang songs together. And, above all, went camping, even in the winter. Those camping adventures bring nothing back but fond memories: making fires in a fire pit and cooking together, including scrambled eggs with fried grasshoppers (if my memory is not playing tricks on me); sitting around campfires and singing songs; roasting marshmallows into smores; hiking in the woods, sleeping in tents. Total fun.

Now, as an adult, I am pretty critical of the scouting movement. It had a strong militaristic streak in it. It was certainly hostile to gays, although this was never talked about at all. It cultivated a certain version of boyhood and masculinity that could over-stress toughness, but then again, helpful, friendly and kind are right up there with other virtues. I don't think I was at all affected by those negative features. Maybe in my Lawrence troupe they were not so emphasized. But it was fun, that is for sure.



Now it is 8:00 p.m. and I am waiting for Marcia's return. I did my mile walk around the loop of the ward, had an undelightful but tolerable dinner, and am listening to Chopin nocturns while I write this journal. Feeling good and content. Making progress on "my writing project", a continuing source of excitement and pleasure.

## Comments

I love your letter to your grandkids! They are so lucky. Thanks for sharing your process so generously, it is very inspiring. Sending much love.

—*Amelie Davidson, September 5, 2018*

Ditto to Amelie. Though I expect that the letter is more of a reminder of the person they already know than anything they haven't heard you say or demonstrate before. I can hear your voice when reading the passage about kindness, for instance. Nice.

—*Ben Manski, September 5, 2018*

It's funny to read this! I don't ever remember your talking about your boy scouting days (or have I just forgotten?) My dad was a professional scout - organized troops, ran summer camps, etc. That's what he did for a job. So I kind of grew up closer to boy scouting than girl scouting, though only on the margins, of course. (But I did spend a lot of time in the family cabins at summer camps.) I was in the brownies for while, but was never that into girl scouting. Now, of course, that I know about the organizations, I see the girl scouts as much more admirable. But even the boy scouts surprise me sometimes by attempting to live up to those virtues. Those virtues mostly are good ones. This is an interesting chapter of your grandchildren book :-)

—*Mary Jo Maynes, September 5, 2018*

Beautiful memories of scouting and a wonderful letter to your grandchildren, dear Erik! You embody all the noble virtues that you identified, but above all, you are the paragon of that kindness. You cannot imagine how much we miss you and your beautiful smiles in the department. Much love!

—*Masoud Movahed, September 5, 2018*

Your thoughtful, kind-hearted, but unvarnished critique of the Boy Scout values reflects your approach to scholarship. Unafraid to take on even the most sacrosanct of institutions, but never in a small or mean way that cuts off continued conversation. It is wonderful to know that you are doing remarkably well, considering the circumstances. Thank you for sharing these thoughts. Warm best to you and to Marcia.



—Margaret Vitullo, September 6, 2018

A nice surprise to read your comments about boy scouts. Your memories--and analysis make the institution far more palatable than I'd thought. Once again, your generous spirit along with critique of course, adds to my understanding. And yes, there are virtue there--and they are yours!

Warm wishes.

—Sonia Baku, September 7, 2018

## Postscript to yesterday's Boy Scout story

September 6, 2018

After writing yesterday's story about Boy Scouts I went to the current Boy Scouts of America website to see what they had to say about the Boy Scout Laws. There has been such turmoil in the Scouts in recent years over the issue of homosexuality, that I was curious if this is reflected in their account of these 12 principles. I then added more material to my letter about this:

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### From the Boy Scouts Website:

#### What are the Scout Oath and Scout Law?

##### Scout Oath

On my honor I will do my best to do my duty to God and my country and to obey the Scout Law; to help other people at all times; to keep myself physically strong, mentally awake, and morally straight.

##### Scout Law

The Scout Law has 12 points. Each is a goal for every Scout. A Scout tries to live up to the Law every day. It is not always easy to do, but a Scout always tries.

##### A Scout is:

**TRUSTWORTHY.** Tell the truth and keep promises. People can depend on you.

**LOYAL.** Show that you care about your family, friends, Scout leaders, school, and country.

**HELPFUL.** Volunteer to help others without expecting a reward.

**FRIENDLY.** Be a friend to everyone, even people who are very different from you.

**COURTEOUS.** Be polite to everyone and always use good manners.

**KIND.** Treat others as you want to be treated . Never harm or kill any living thing without good reason.

**OBEDIENT.** Follow the rules of your family, school, and pack. Obey the laws of your community and country.

**CHEERFUL.** Look for the bright side of life. Cheerfully do tasks that come your way. Try to help others be happy.

**THRIFTY.** Work to pay your own way. Try not to be wasteful. Use time, food, supplies, and natural resources wisely.

**BRAVE.** Face difficult situations even when you feel afraid. Do what you think is right despite what others might be doing or saying.

**CLEAN.** Keep your body and mind fit . Help keep your home and community clean.

**REVERENT.** Be reverent toward God. Be faithful in your religious duties. Respect the beliefs of others.

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I especially liked the clarifications of:

**Loyalty** as caring for people and communities you value. I would add to this "taking care of" rather than just caring.

**Helpful** as not expecting a reward for helping others, which is a very nice way of saying that helping should be a response to a need in others rather than any desire for direct personal benefit (other than from feeling good for helping).

**Friendly** as being a friend to people who are different -- that is very close to what I had said.

**Cheerful** (which I had forgotten about in my list) as trying to help others be happy. I hadn't thought of that as one of the virtues of cheerfulness – it is not just that it makes oneself feel better; it makes others happy as well.

**Thrifty** as including not wasting natural resources. They could have put environmental concerns

under loyalty as well, which would have been good: caring about the environment.

**Brave** as doing the right thing despite what others might think. That is a powerful point that I hadn't thought of.

Those are major, and important, ideas that I don't think were part of the official explanation of the Boy Scout Laws 50 years ago. So, perhaps, the Boy Scouts are really changing.

## Comments

Apparently you can now get a merit badge for game design. Seriously. The times they are a changin'.

—John Gastil, September 6, 2018

they now have a "labor" merit badge

[https://filestore.scouting.org/filestore/Merit\\_Badge\\_ReqandRes/American\\_Labor.pdf](https://filestore.scouting.org/filestore/Merit_Badge_ReqandRes/American_Labor.pdf)

—Matt Nichter, September 10, 2018

## Leukemia versus NBSMG

September 8, 2018

Since 1981 I have been a member of a group of mostly economists, philosophers, sociologists, and political scientists that has met more or less every year to discuss theoretical and empirical problems linked to Marxism, socialism, and social justice. The first meeting in 1979, of what eventually became the group, discussed the extraordinary Marxist philosopher G.A. Cohen's book, *Karl Marx's Theory of History: a defense*, but soon the topics and themes diversified. The initial meeting in 1979 had a couple dozen participants and they seem to have had such a productive meeting, that some of the participants decided to have a smaller follow-up in 1980. I was invited to participate in 1981, because mainly (I think) of a review essay I wrote of Cohen's book, along with my earlier work on class; and I have been a passionate member of the circle ever since.

There were several names we gave the group:

- Most lamely, "The September Group"
- Most rigorously, "The Analytical Marxism Group."
- And for internal consumption, "the Nonbullshit Marxism Group," abbreviated as the NBSMG, which in more recent years in my communications I altered to the NBS(M)G in recognition of the fact that most of the group no longer strongly identifies with Marxism.

Membership in the group has changed over the years, but there has been a core of people who have come nearly every year since the mid-1980s. At the outset it entirely consisted of men (this was always a source of some embarrassment); now we have two permanent women members of the group. In the early years, our routine was to circulate five or six papers from the members ahead of time, spending one and a half hours or so on each paper. Over time, the format of the gatherings has changed. Now we only have three or four members of the group present papers and invite guests to fill out the two-day event.

Here's the main thing: This group of scholars has constituted the most powerful influence on my work for almost four decades. The discussions are often very tough, but they have pushed me to formulate my arguments in my work in a more precise, analytically rigorous way than is typical in sociology. My work on class and exploitation developed in intensive dialogue with John Roemer's work on the same topic; my very explicit effort to anchor my agenda in serious normative discussions would not have had the rigor it has without the many years of discussion with everyone in the group of the various currents of egalitarian understandings of social justice; my work over the past 25 years on Real Utopias would not have developed in the ways it has without having been constantly pressed to make explicit underlying assumptions and to worry about unintended consequences; and for sure, I would not have been exposed to so many ideas outside of the outer bounds of the Marxist tradition but which nevertheless bear heavily on my concerns.

Every year -- with a few exceptions -- we have met, first in London, then Oxford, once in Paris, and now every year in New York to intensely explore some of the most important themes in progressive scholarship. Just as important as the intellectual content of these meetings, I always look forward to seeing everyone and hanging out. The event has become, for me, as much a reunion among close friends as a stimulating academic event.

For the past few years I have been the main coordinator of the meetings. I'm good at that kind of administrative task, and actually sort of enjoy it. This year the papers slated to be presented by both guests and permanent members looked exceptionally interesting. And then, on April 4, I was diagnosed with acute myeloid leukemia. At first I thought that maybe by September 8 I would be able to travel and participate. Little did I know what was in store for me. But, of course, I knew that I couldn't carry on coordinating, and it wasn't totally clear what was going to happen.

To my relief, Philippe van Parijs and Suresh Naidu volunteered to take over, and so the meeting began this

morning. I skyped in to say hi to everyone and then we made plans that if I was up to it, I could later skype in for some of the sessions. Jenny, Mark and Safira were visiting in the morning, so I couldn't participate in the meeting then; and then I had an energy crash and was out of action for an hour and a half or so. But by mid-afternoon New York time I could join via cyberspace. It was wonderful, even though I couldn't actively participate in the discussions because of fatigue. Tomorrow I hope to participate more, but judging from past cycles of chemotherapy, I will be on a downward trajectory for a few days. I am now neutropenic and very tired. But we'll see.

## Comments

Post transplant you. will be off to NY for the annual meeting.JJ

—John Posner, September 8, 2018

## A weird day: miserable and magical and somewhat wacky (with mini-medical update at the end)

September 10, 2018

**Miserable:** On Saturday night I had what is called a neutropenic fever -- a fever spike associated with having no neutrophils (ANC=0) and no other forms of white cells. The causes of most of the fevers that occur in this condition are never diagnosed but they can really make you miserable. I was miserable.

When the fever initially spiked the doctors did not want to give me anything that would suppress the fever, since they needed to know how severe this was. So, for the first two hours or so I had to endure chills and generalized malaise. I tried using some breathing techniques to calm the chills and incipient shaking, and maybe it helped a bit because I never developed full-blown rigors (violent, uncontrollable shaking) like I did one time in the summer, but throughout this period I felt on the verge of tipping over to more violent chills.

During that time there were lots of blood draws to get cultures for various kinds of infections, but I wasn't sleeping anyway so that didn't matter. Eventually I was given a hospital-level dosage of Tylenol, and to my and to my surprise it quickly did the trick. I think of Tylenol as less effective than ibuprofen, but it worked like a charm and I slept through till morning.

I had wanted to try to participate in the presentations of the NBSMG, but when I woke up on Sunday this just

seemed impossible. I was enfeebled. That is a new form of in my fatigue-lexicon:

- Debilitating exhaustion
- Sleepiness
- Wistful drowsiness
- Depleted energy
- Out of breath
- sluggishness
- Weakness
- Enfeeblement

Enfeeblement is being unable to do things like lift myself to a sitting position in bed, not just feeling weak. If, before getting sick, I tried to lift a 100 lb bar bell I would know that I did not have the strength to do it, but I could exert my muscles sufficiently to feel real resistance. This feebleness went deeper. This was a new thing. I wasn't scared about it – I understand that the chemo, along with the collapse of my immune system and a fever can do strange things. But it seemed to rule out even dipping into the NSBMG meeting. I sent a message saying I didn't think I'd be able to Skype, but the group said that they would keep skype open just in case.

I dozed some more, had another Tylenol. My nephew and his fiancé came for a visit, but I still was pretty much out of it. I was carted down to the bowels of the hospital for a chest X-ray, but this required full assistance from the transporter to get me out of bed. Still, when around 1:30 CDT I was brought back and in bed, I decided to skype into the meeting in NY since maybe I could just listen.

**Magical:** They were delighted to have me join them, but for me the next three hours were exhilarating. I listened in on two discussions one on the economic structure of global capitalism and why it set the stage for WWI, and second on the difficult issues for which the left does have decisive answers.

The first discussion centered on an by argument Suresh Naidu about the economic foundations of imperialism: As industrialism increases, the rate of return on capital declines and inequality increases. Wealthy people save more than poor people, and thus savings increase, but with lower rates of return. Rates of return are higher if the wealthy invest more of their capital in less developed regions, especially where there are minerals and primary commodities, but such investments are inherently riskier than domestic investment. Militarism and colonialism reduce those risks by protecting sea lanes and repressing resistance to colonial extraction of primary commodities. This means military spending ramps up as states want to protect their national capitalists. This

creates a context in which a trivial triggering event can lead to war. Then all hell breaks loose.

The second paper ranged over many of the questions for which the left does not have entirely satisfactory answers: Innovation, equality and democracy; Modern Monopoly (a technical term for things like Google and Facebook); corporate governance, taxation and the limits of anti-trust; High wage labor in a world of massive labor surplus (China and India especially); Robots and the future of work in the caring & knowledge-based economy; and the political and economic representation of the less well off in the service based economy. Sam Bowles gave a fantastic introduction to the themes. The discussion flowed from one person to another with easy give-and-take. There was none of the often somewhat aggressive flaw-centered criticism that has marked many of our discussions over the years; the spirit was much more, "what interesting ideas! Let's explore them, see where they need sharpening," rather than "how here's what is wrong-headed in what you are arguing". Flaw centered discussion can be useful, but it can also be dispiriting. I was mostly a happy spectator -- on my usual role -- but I felt completely immersed in the world of these ideas and the excitement of leaning things that were difficult, deep and important. The next meeting will be over Labor Day Weekend 2019; I so hope I will be able to attend.

**Wacky:** To end the day I decided to watch the Green Bay Packers opening game of the season **against the Bears**. In the first half they were awful. At half time they were behind 20-0, and to make matters worse, the hyper-star QB Aaron Rodgers was injured early in the game, so it looked not only that GB would lose the game, but that their whole season would be a catastrophe. So, I turned off the game. I love watching football even though I hate the values it mostly embodies and the ridiculous level of injury to players. But the narrative structure of football is hard to bet. Each game is really story, and the best games have a fantastic narrative arc.

On Sunday morning I learned that Green Bay had entered the 4th quarter down 20-3. Rodgers was back at QB. Green Bay scored three touchdowns and won 24-23.

**Mini-medical update:** Feeling much much better. Fever is down. No longer feeble. Plenty of energy to write. Taste buds back to their scrambled state where almost nothing tastes palatable. She Marcia just got back with ice cream and gelato. Maybe that will at least get some calories in me.

## Comments

Erik --

I am sorry to learn of all that misery, except that it has passed.

"Department of Great Minds Think Alike" --

I, too, turned off the Packers-Bears game when it was 20-0.

But, evidently and fortunately, neither of us Great Minds is always right.

Cheers!

*—Robert Hauser, September 10, 2018*

## Reflections on "accomplishing something" in a day

*September 11, 2018*





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**mini-medical update:** All the symptoms of the weekend are gone. I feel fine, full of energy, no feebleness. White count is still zero. But nothing really to report.

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I have had a calm and quiet day in room 14 on the 7th floor of CFAC. Marcia went to Madison for the day to take care of various odds and ends, and I've been here to write in my letter to my Grandchildren and be gently taken care of by the medical staff of Froedtert Hospital.

At one point, the thought "maybe I should take a nap," wafted through my mind, but then another thought intruded: have I "accomplished" enough today? What? I'm in the acute myeloid leukemia ward of a hospital in the recovery faze of a chemo cycle that has wiped out the white blood cells in my peripheral blood. I just had a weekend of utter exhaustion. I now feel physically and mentally good. And still I ask of myself each day, "what have I done that matters?" I didn't call forth that question in a straightforward conscious sort of way; it just spoke to me, like in cartoons where there is an angel and a devil sitting on someone's sholders asking questions and giving advice. Well, my devil or angel (take your pick) was checking on me: have I accomplished enough?

This is (I think) an important part of my inner life: I work constantly on projects with purposes, and I feel the need or urge -- but not mostly outside pressure -- to make progress on whatever project I am doing. So, here I am in the midst of serious medical treatment, but somehow I don't see my own healing as a "project" in the sense I'm talking about. For me, I guess, a project is about something I am making, doing, creating. I know (or perhaps more accurately: I vaguely remember...) that Sartre characterized a life as a project, and there is something to that. But what my devil/angel was asking me about was progress towards the completion of something I was creating.

When I was diagnosed with AML in April I was in the midst of several serious projects of this sort: the How to be an Anti-Capitalist book; the final editorial work with John Gastil for the Real Utopias Project book on Legislature by Lot; planning the conference for the next book in the RUP on Democratizing Finance to be held in Madison in July; and preliminary planning for the RUP conference and book on Isabelle Ferreras' proposal for Democratizing the Corporation. I managed to pretty quickly find other people to take the leadership roles on all on the real utopias project work, and somehow by July I managed to complete How to be an Anti-capitalist. As I remarked in some post, my to-do list was empty (except for letters of reference and the like, which keep popping up -- as they should). And that felt terrific, given the circumstances.

But in my heart I didn't want to be project empty. This blog has become a project for sure, and one that is deeply meaningful to me as I talk to all of you several times a week. And the letter to my Grandchildren is definitely a project. I've written nearly 30,000 words and enjoying every minute I spend on it.

These projects are different, however, from my usual academic projects. In all of those projects in one way or another I create obligations to other people who depend on my contributions to seeing the project to fulfillment. This has been the case from the start for the Real Utopias Project. Each step in the process depends on my pushing things forward: finding, or sometimes writing with a colleague, a manuscript that proposes some real utopian alterative to existing institutions; revising that proposal on the basis of pre-conference presentations and

discussions; recruiting participants in the conference and getting them to actually write pieces that engage the proposal; organizing the conference itself (although that always involves wonderful staff support from the Havens Center); providing feedback on the papers from the conference; dealing with the papers that are not up to the required standard for the book; and on and on. On those projects I feel good when I have accomplished something that counts as progress towards completion. This is also true for my own books: finishing *How to Be an Anti-Capitalist* was also fulfilling a promise to my publisher that I would do so, and to the many people and audiences I have told I was writing book. For these academic projects there is always a shadow of external pressure, even if this nothing like the pressure on young scholars to finish books because of tenure, grants, promotions, and such.

Instead of a nap, therefore, I wrote this blog post. Now, for sure, I can say I have accomplished enough for the day: 1000 words or so on my letter to my Grandchildren (mostly about biking and camping) and thoughts on making progress on making projects. In some ways it seems nuts to me that I have this particular disposition. Shouldn't I just "give myself a break" and relax? Binge watch on Netflix? And for sure, TAKE A NAP! The very question, "have you done enough" carries with it whiffs of puritanism: one must strive to accomplish things to demonstrate one's worthiness to God. While salvation by God doesn't figure in my self-understanding in any way, this strong internal disposition certainly does undergird a pretty potent "work ethic." I do not think of myself as a workaholic. That signals people who work like maniacs out of compulsion rather than people who spend lots of time working on things because of the fulfillment and meaning they get from those activities.

In a way, then, my very strong need to introduce these two projects so consistently into my daily routines might be viewed as a diagnostic on the underlying character of my inner drives towards projects. That sounds a bit overblown, but here's my idea here: The academic projects always are a mix of inner-drives to do something worthwhile and meaningful, and webs of social relations in which I other people depend on me following through with tasks. I have mostly shed the second half of that sentence. I say "mostly" because I am deeply moved by the reactions of people to what I have written in these journal entries, and those reactions inherently become part of my self-understanding of what I am doing, and thus part of why it matters to me that I "accomplish enough." [Don't worry: I do NOT in any way experience this as pressure to write because you are reading this. It is an important part of the pleasure of this writing project that we are together as I write.] The hard core of my need for projects, I think, is therefore reflected my letter to my Grandchildren. This has a deep purpose. It will, I think enrich their lives. But it isn't the result of any external sense of obligation or pressure.

And only I can do it. I haven't formulated this idea in this way before: If I don't write this letter no one else will and nothing else could substitute for it.

One final thought on all of this, even if it is a bit of a meandering digression. I have always made the distinction between the great historical accomplishments of scientists and of artists -- composers, novelists, painters, playwrights and the like. If Newton had died in the English plague of 1665-6, which was entirely possible, Newton's laws would still have come about eventually, although they would have been called by some other person's name. Without Darwin, we would still have evolution by natural selection. Without Einstein, we would still eventually have the theory of relativity. These are full-blown discoveries of how the world works, even if they subsequently get revised and reconstructed. But without Beethoven, there would be no Beethoven's fifth symphony. Without Shakespeare, no *Hamlet*. There probably would have been a Romantic period in the

development of Western Music, of course. So there is a level of abstraction of descriptions of Beethoven's Symphonies in which his own creative identity doesn't matter. But in the powerful details of what he created he mattered: without Beethoven there is no Beethoven. That is not true for Watson & Crick: the double helix structure of DNA would have been discovered by someone -- probably close in historical time -- and we would eventually have discovered the translocation mutations that caused the particular nastiness of my acute myeloid leukemia. [By the way, as a digression within a digression: I just learned today that another label for my special mutation is EVIL, which the doctors refer to -- quite rightly -- as the evil mutation].

So, scientists make discoveries; artists, at their best, create new worlds. What about sociologists? I'll open a can of worms: I think what is wonderful about sociology is the messy way it does both. We make discoveries about the world, reveal how it "really works" as best we can. But we also invent new ways of thinking about the world that shape the way people make meaning in their lives and act in their social world. Some of the ideas that sociologists (and, of course, their family friends in other social sciences) pour into the world affect the ways the world works. These are not simple discoveries in the usual sense. This is why it makes sense to read Marx and Durkheim in the 21st century, while few evolutionary biologists read Darwin and fewer physicists Newton, unless out of pure curiosity.

We are entering murky philosophical waters. I have written that the maximum possible speed that anything could travel was the speed of light, roughly 186,000 miles/second, prior to Einstein's discovery that this was the case. The discovery did not create the limit. In social life, on the other, the limits of what is actually socially possible are in significant ways shaped by people's beliefs in what is possible. The beliefs in alternatives affects the actual possibilities of alternatives to the world as it is. And thus, social theories of possibilities -- which can become the beliefs of people -- can themselves affect the limits of possibility. But of course, there are limits-to-limits; there are fantasies of alternatives that under no circumstances could constitute the bases of viable social structures and institutions. Beliefs can be pure wishful thinking. In sociology there is thus a dance between a science of how things work and sociology of the creative possibility: possibility disciplined by a demand for specification of mechanisms. Enough already! Even meandering digressions need limits.

I guess I now can say I have accomplished enough for the day. I'm glad I didn't take a nap.

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**Postscript:** I have attached a photo from this year's NBS(M)G meeting in which Suresh is holding up a photo of me, along with last year's photo. I thought you would like to see the people I was writing about yesterday.

## Photos



## Comments

Your meandering digressions are so informative!! I am also glad to hear that the weekend symptoms are gone. Sending you big hugs and much love, dear Erik!

—Masoud Movahed, September 12, 2018

## Two encounters of wonderful sociological and personal significance

September 14, 2018

Warning: This will be my most academicky posting....

Yesterday I was suddenly doing fieldwork of the richest sort (with no IRB approval). I live in a wonderful fieldwork site, a social world so different from the one I usually inhabit. I'm a participant observer and integral member of this social world. I am doing both theoretically-driven research looking for real utopian moments that can deepen my understanding of my own theoretical agenda and grounded theory where I am open to encounters/observations/experiences for which I have almost no theoretical preparation. Both playing off each other, each generating new ideas and insights in different ways. Enough prologue. Now for the encounters.

## 1. Real Utopia

### *Descriptive notes of some conversations*

September 12. I had a lovely conversation with the resident doctor on the floor, an engaging young woman clearly very interested in her work, the science and the caregiving. I told her the detailed story of how my acute myeloid leukemia (AML) was diagnosed right after a diagnosis of *diabetes insipidus* (DI), a failure of the anti-diuretic hormone (ADH) needed to regulate sodium. I mentioned that Dr. Hari did a case search and told me that he found 12 cases in which AML was diagnosed right after DI, and in six of these there was my specific set of mutations. So he was convinced of a causal link. I then told this to my endocrinologist in Madison and asked if this meant that if I am cured of the AML, the DI will disappear. Unfortunately, he said, once the neurons linking the hypothalamus to the pituitary gland are damaged they won't grow back.

She then said that she had heard that DI declined when the AML was gone. At the end of our conversation, she said that she would see if there were case reports about this.

September 13. This morning she arrived and said she had found two case reports in which DI disappeared after A full cure of AML. What is more, both cases had the same mutations as I have. The critical mutation was the translocation mutation, which as I recently learned was also called the EVIL mutation, or colloquially, the *Evil* mutation. Apparently, EVIL directly suppresses the anti-diuretic hormone, and sometimes this is sufficiently intense to create DI. This happens without any interference at all with the neural connection between the hypothalamus and the pituitary gland. So, once EVIL is destroyed by my new immune system, the diabetes insipidus just disappears!

I told her that now I will have two reasons to celebrate a year from now: I will be alive and I won't have diabetes insipidus. This mutation is really Evil. Not only does EVIL attempt to kill me, but it devises a way to be extra annoying during the process. EVIL is both Satan and Coyote. Later in the day, the attending doctor for the week came by. I told him how wonderful the resident had been and how happy I was by the news. He said that this particular resident planned to go into hematology oncology and so she always wants to learn more about the disease. He added more information. EVIL causes all sorts of mischief in the body. It does not infiltrate organs and cause damage like some other cancers. Rather it mucks around with all sorts of immune effects. Some people get rheumatoid arthritis from EVIL. Sometimes this is before the diagnosis of AML; sometimes afterwards.

### *Sociological analysis*



One way of interpreting these descriptions is that this is the result of the serendipitous conversation between a chatty, enthusiastic professor who is curious about his disease and an eager young doctor who is also curious about all aspects of this disease because she plans to specialize in its treatment.

There is nothing false about this interpretation. The particular, concrete individuals do matter in the story, and their pairing certainly does have a haphazard quality. But it also misses something fundamental.

The Center for Advanced Care is organized in such a way as to enable such chance encounters having different kinds of effects than they would otherwise likely have. I don't think it makes such chance encounters between these sorts of people more likely. If I were in a more traditional ward, I would still have interactions with eager, curious young doctors. The probability of a person of type X (me) and type Y (the eager young doctor) interacting might be the same. But the outcome would almost certainly be different because the social structure of CFAC enables a different range of actual interactions within such chance encounters: deeper conversations; looser role constraints on the interactions; greater possibility for the dispositions, needs, and vulnerabilities of the people in the interactions to become known to each other. This is possible because of the low staff-to-patient ratios, the rejection of harsh efficiency treatment of time, and many other things.

For other people with different characteristics, different kinds of new possibilities from encounters would also be opened. The broader point is this social structure expands human-flourishing, both by direct effects on care, and by enabling new positive effects.

This is an instance of a real utopia. Froedtert hospital might not itself be a real utopia, but within it there is this special enclave. This is one aspect of the way in which health care would be practiced in a society built around emancipatory values. It is a building block of the alternative.

In most of my work on real utopias I emphasize the direct effects of emancipatory institutional designs: how changing the rules of the game of democratic competition undermines the power of the wealthy; how new redistribution mechanisms like basic income give power to a broad class of people to say no to capitalist domination; and so on. There are places where I pay attention to the effects of institutional structures on micro-dynamics, such as my discussions of how different parental leave systems shape the dynamics of childcare negotiations between mothers and fathers. In those discussions, however, the focus is on individuals characterized as abstract types (mothers and fathers) rather than specific individuals with particular characteristics. What struck me in the episode here is the way the dynamics between people described in a much more fine-grained way are affected by structure. [As I write this the analysis is getting murky: time to stop!]

## **2. A surprising (to me anyway) social reality revealed in a conversation with a nursing assistant**

The following is a conversation (reconstructed from memory, but substantively accurate) between me and a black woman who at the time I thought was in her mid to late 60s, but later was told was in her early 50s. I will call her Suzie.

I was writing on my laptop at my table with *Carmina Burana* playing pretty loudly on the Bluetooth speaker

linked to my iPod.

Suzie: Good morning. My name is Suzie. I'm going to be the nursing assistant this morning. I'm a floater filling in for someone. I work all over Milwaukee.

She looked closely at me.

Suzie: Are you a preacher?

EOW: No, I'm a professor?

Suzie: You seem like a preacher or minister.

EOW: (I smile), No, I'm a professor at the University of Wisconsin in Madison.

Suzie: In Madison? I thought the University of Wisconsin was in Milwaukee.

EOW: There is a University of Wisconsin campus in Milwaukee, but also one in Madison.

Suzie: That one must be pretty small.

EOW: UW Madison is really big, 35,000 students.

Suzie: I've heard of UW Madison, but I thought Milwaukee was the main University of Wisconsin.

She then turned her attention to the music

Suzie: Is that Gospel music? Seems like Gospel. I love Gospel.

EOW: No. That is a wonderful piece of music for orchestra and chorus. It's called Carmina Burana and was composed by a Swiss Composer named Carl Orff. The words are in Latin from some medieval poems.

The music frolicked on.

Suzie: Do they perform that music in a Church?

EOW: It's possible somewhere, but this was recorded in a big concert hall somewhere.

Suzie: The music seems to have the holy spirit in it.

EOW: I guess lots of different kinds of music share the same spirit, but this isn't religious music. It was written for concerts. [I didn't mention that the Latin poems were mostly bawdy]

We continued talking. She really seemed unaware that there were large concert halls in which music was played by large symphony orchestras.

She asked something about my work and somehow this lead to me mentioning that In had participated in a meeting in my university Department by video conference while I was here in hospital.

Suzie: Really? How'd you do that?

EOW: On the computer.

Suzie: I didn't know you could do that.

EOW: Let me show you.

She came over to my table. I opened Skype and went to tools to test the webcam, and there we were, next to each other. She seems genuinely surprised that a laptop had a camera and that this could connect to a meeting in Madison.

While we were talking she was also taking my "vitals" – blood pressure, temperature, heartrate and blood oxygenation. After 20 minutes or so she had to move on to her next patient.

Suzie: It's sure been nice talking to you.

EOW: I enjoyed it a lot too.

### *Some comments*

I know, of course, that there are subcultures and communities in the United States that have very little knowledge and understanding of the social world I inhabit, and of course I have little knowledge of theirs. What was surprising to me was that a person who was certified as a CNA and worked on the patient wards in hospitals all over Milwaukee would have such little knowledge of the UW Madison, of concerts, or of the technical capacity for a video conference. She does not live in a world completely isolated from interactions with academics, doctors, the wider institutions of the society. And she is sociable and chatty, and seemed to be curious. My prior assumption was that someone with her education and worklife and style of social interaction would be at least a little familiar with things like concerts, UW Madison, and video conferences.

Of course, this is one person. One data point. It may not be the case that everyone in her community is like her in this way. Nevertheless, this was a disruptive data point for me.

## **Comments**



Good stories. Agree with the institutional design part about the hospital, and wondering about the institutional design that gave you the Milwaukee option for treatment. As for the profound ignorance of the lives and assumptions of others, I've found that I'm often profoundly ignorant of the realities of the lives of people who are not in my academic circle, just as they know little about the world centered on universities.

—*Pamela Oliver, September 14, 2018*

## Medical Update [second of two postings today]

*September 14, 2018*

### *The serious version*

I have been feeling extremely energetic over the past five days or so – little fatigue with almost no annoying symptoms. I have been 100% neutropenic – zero white cell count – but the doctors say that is normal for the FLAG chemo. I shouldn't expect the WCC to begin to increase for a few more days. Marcia was in Madison for two days and most of the time I spent writing and reading.

Marcia returned late afternoon yesterday. We went for a mile walk in the corridors, and then started watching *The Way*, a movie directed by Emilio Estevez. Then, pretty suddenly around 10:30, I crashed. My energy just seemed to evaporate. So, I went to bed.

Labs were drawn at midnight as usual. I woke up around 3:30 with a mild headache at the back of my neck. Not too bad – 2 maybe on the proverbial 10-point scale. The nurse told me that my hemoglobin was now 6.8, so I would get a unit of blood. They were just waiting for the type & cross to match my blood with the blood bank.

Went back to sleep, a bit fitfully. At 7:00 I was up for good, still with the mild headache. The transfusion was started; vitals taken – all normal. The medical student came to check me over as usual, then the resident. I described the headache which seemed a little worse. Then at around 10:00 or so it got a lot worse. My blood pressure is almost always somewhere around 115-120/60-70. This time the systolic number was 168. The headache intensified. The systolic number increased to 173, then 184. I described the pain as 6 or 7, but then more like 8. I felt awful.

The medical team went into action. A CT-scan of my head was ordered to check for bleeding, since I was on a mild blood thinner because of the small clot near my PICC line. Quick-acting blood pressure lowering medicine was ordered. By 10:30 the worst was over. I was wheeled down for the CT-scan. The scan only took a few minutes, but adding the transport and waiting, the whole thing was more like an hour and half. No big deal.

Back in the room by 1:00. The pain was gone. The plan ahead is that I will be given IV blood pressure medicine if there is another episode, but for that, if it were to be administered, I would need heart telemetry. Five leads were then glued onto my chest and hooked up to a portable telemetry device which I will wear in a pouch around my neck for a few days in case it is needed.

CT-scan came back 100% normal. Untreated blood pressure now 122/72. Another day, another drama. This is a predictable sort of thing to happen in the recovery period after an AML chemo.

### *The Big Five Safari version*

In South Africa, one is told that there is a list of “The Big Five” game animals one hopes to see: the lion, leopard, rhinoceros, elephant, and Cape buffalo. Apparently (according to Wikipedia) the name refers to the five most difficult animals in Africa to hunt on foot. On a Safari it is a source of pride to see them all. On my one Safari, I only saw three.

I figured that there must be a Big Five for AML cancer patients: the most awful side-effects of treatments. It would then be an accomplishment to hit all of them. Here’s my list: Severe Nausea, Searing Headache, Relentless Coughing, Debilitating Exhaustion, Intransigent Constipation.

Coming into the present expedition, I had bagged three of the five: RC, DE & IC. But SN and SH had eluded me.

No more! On Day 2, Severe Nausea was captured, if only briefly. While nasty, my SN was relatively small and easily tamed. Finally, today, day 14, I encountered my first Searing Headache of the entire AML saga. Sure, there were occasional MH’s (minor headaches), but those are easily ignored. But only today did a proper SH make an appearance, backed by a nasty 184 systolic.

So, my list is complete. No need for any of them to reappear. You don’t get extra credit for 3 SNs + 9 DEs + 2 ICs. The check-off list says this explicitly: one check per Big Five. What a relief: from here on out, until I am fully recovered from the bone marrow stem cell transplant a year from now, I will be filled with energy and at ease throughout my body.

## Comments

DI is an unusual disorder. Fortunately easily treated. Sounds like you are holding up well. Hopefully your counts will soon bounce back. JJ

—John Posner, September 14, 2018

Hopefully the "Big Five" are gone and never back again. Sending you positive vibes, big hugs, and much, much love!

—Masoud Movahed, September 14, 2018

Congrats (?) on getting all five. Yikes.

—John Gastil, September 15, 2018

## The weirdness of feeling good & update

September 15, 2018

Yesterday I felt about as miserable as anytime during my illness. The depth of miserableness only lasted a half hour or so, but the headache and blood pressure spike was terrible for that period. Today I feel totally wonderful -- absolutely no symptoms, not even a shadow of fatigue. Yesterday I was reminded that I am really sick; today I feel how can I possibly be sick and feel this good? The attending doctor was surprised as well and didn't have an explanation either for yesterday's blood pressure spike or today's vitality. Maybe this is just another devious strategy of the trickster in the EVIL mutation -- the Norse Loki, the Hopi Kokopeli, the Welsh Gwydion; they all like to mess with me, yank my chain. I'll take it. I won't be fooled into complacency, just enjoy the moment.

I now have pretty solid new information about the donors & the transplant:

1. Two donors have been definitively cleared: healthy and ready to have their stem cells harvested.
2. I am scheduled to have all of the tests that were done for the previous randomization day redone next week, since they cannot be older than 30 days when the randomization occurs.
3. My bone marrow biopsy to assess my remission status will be on the 20th.
4. I will be discharged from here when my red blood cells and platelets are sufficiently stable that I will only need one or two transfusions aweek, rather than nearly every day like right now. That will probably be in a week or ten days.
5. If all goes as currently planned, then I will come back to Froedtert for either the transplant or salvage group (which is pretty much the same kind of treatment I'm having now) around October 15.

Of course, we've been through this before: pretty firm schedules with anticipated dates for the transplant, only to have things derailed for one reason or another. But, no point in fretting about this.

That would only make Loki grin.

## Comments

Good that this schedule is now in place!

*—elliott sober, September 15, 2018*

Two donors cleared, healthy and ready to go! Yay!!!!!!!!!!!!!!

*—jeannette golden, September 15, 2018*

What Jeannette said!

*—Cathy Loeb, September 16, 2018*

Glad you're feeling wonderful for the moment. Hoping the moment lasts as long as possible!

*—Josh Wright, September 16, 2018*

Great to see two donors cleared definitively, Erik. And glad to read your energy has been on the up and up and you've been able to find equanimity amidst your challenges.

*—Adam Szetela, September 19, 2018*

## medical update with not much to report

*September 17, 2018*

This week will involve a series of labs and tests needed for the clinical trial which had to be repeated because they must be within 30 days of the randomization. Yesterday at around 3pm my nurse got a call from the CT-Scan department saying that they had received orders for sinus and abdominal scans with iodine infusion to create contrast. and that that transport would be up in 20 minutes. Marcia asked the nurse about the timing. The last time I had these tests I had explicit instructions to fast for four hours before the tests because of the iodine contrast dye. I had just had lunch, so the nurse called the CT scan department to check this

out. They said it wouldn't be a problem. So down I went for the scans. I had felt terrific before the scans. After the scans I felt queasy for the rest of the day. The CT scan team clearly was taking a cavalier attitude towards the four hour fast. AS far as I know this was the first time at Froedtert where this sort of thing has happened to me. Not serious, but annoying.

Other than that wee episode, I've been feeling extremely peppy most of the time for the past week or so. I'm still waiting for my white cell count to rise above zero and for neutrophils to reappear; the doctors tell me that this should happen in the next few days. The plan is still that I will be discharged on Friday, but there is some new uncertainty about when the bone marrow biopsy will happen -- either the 20th or the following week. I'm used to changes in plans, delays and uncertainty, so this doesn't bother me.

Currently I am getting two shots a day in my belly -- one, a drug that stimulates white cell production and the other, a blood thinner. When I leave here I will have to do these myself. I did this today and really it is no big deal.

## Comments

The uncertainties are indeed annoying, dear Erik! Here waiting with you for the white cell count to rise and for the neutrophils to reappear very soon - Much love!

—Masoud Movahed, September 17, 2018

Why do you have to continue the blood thinner shot at home? Isn't this to compensate for low mobility in the hospital? In any case, great to see you managing these inconveniences and changes in scheduling with such equanimity. There's no point in getting worked up about such things, but few can avoid it! love, devah

—Devah Pager, September 17, 2018

So complicated.

—Sarah Siskind, September 18, 2018

Te acompañamos desde Argentina Erik, fuerza y paciencia! Abrazo.

—Rodolfo Elbert, September 18, 2018

## Medical Update: almost 100% certain plans

September 20, 2018

**FLU/TBI SIERRA STUDY MUD PBSC TRANSPLANT CALENDAR FOR  
ERIK WRIGHT (AML)  
DR. HARI: 414-805-6817 COORDINATOR-BRENDA MILOTA RN; 414-805-1286  
OCTOBER/NOVEMBER 2018**

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Start Thyroid Protection	1 TBD 2 <sup>nd</sup> Floor Cancer Center Lab TBD 3 <sup>rd</sup> Floor; Center for Advanced Care Building (CFAC) Intravenous Radiology (I.V. Placement) IMAGING #1 FOR DOSEMETRIC DORS	2 Nuclear Medicine Dosemetric Dosing	3 Day -21	4 Day -21	5 Day -21	6 Day -15
7 Day -18	8 Day -17	9 Day -16	10 Day -15	11 Day -14 ADMIT BMT: PLEASE CALL CFAC FOR ADMISSION TIME 414-805-1286	12 Day -13 Therapeutic Dosing & ISOLATION Starts: 3-6 Days!	13 Day -12 ISOLATION
14 Day -11 ISOLATION	15 Day -10 ISOLATION	16 Day -9 ISOLATION	17 Day -8 ISOLATION	18 Day -7 ADMIT BMT: PLEASE CALL CFAC FOR ADMISSION TIME 414-805-1286 FLUDARABINE (Chemo)	19 Day -6 ADMIT BMT: PLEASE CALL CFAC FOR ADMISSION TIME 414-805-1286 FLUDARABINE (Chemo)	20 Day -5 FLUDARABINE (Chemo)
21 Day -4 FLUDARABINE (Chemo)	22 Day -3 REST DAY Start Tacrolimus (Anti-Rejection)	23 Day -2 TBI #1 (Total Body Irradiation) RECEIVE DONOR CELLS; TRANSPLANT (DAY) Start Cyclosporine (MMF) (Anti-Rejection)	24 Day -1	25 Day 0	26 Day 1	27 Day 2
28 Day 3	29 Day 4	30 Day 5	31 Day 6	1 Day 7 NONUMERG	2 Day 8	3 Day 9
4 Day 10	5 Day 11	6 Day 12	7 Day 13	8 Day 14	9 Day 15	10 Day 16
11 Day 17 Discharge This Week...	12 Day 18	13 Day 19 Recovery Time: 6-12 Months...	14 Day 20	15 Day 21	16 Day 22	17 Day 23
18 Day 24	19 Day 25	20 Day 26	21 Day 27	22 Day 28	23 Day 29	24 Day 30
25 Day 31	26 Day 32	27 Day 33	28 Day 34	29 Day 35	30 Day 36	31 Day 37

September 22, 2018/Thu

It seems that finally we are very close to a definitive plan and schedule for the stem cell transplant. Of course, with all of the surprises and unexpected delays in the past I think nothing is 100% until after it happens. Still, here is the story (with a lot of details for those of you interested in details):

**1. Bone marrow biopsy** to determine whether or not I am still am classified as refractory acute myeloid leukemia is scheduled for tomorrow, Friday, September 21st, at 1 pm. There is an interesting story behind this date. If there was no clinical trial in the picture, the biopsy would be one week later, September 28, four weeks after the beginning of the chemo. This would provide enough time after the end of the chemo to be sure that if there appears to be a remission, it is a robust remission. Last April I had a biopsy on April 30, only three weeks after the beginning of that first cycle of chemo. It showed that my bone marrow was clear -- no sign of disease. This triggered preparations for the transplant. Two weeks later we had a second follow-up biopsy to confirm the results of the first. This one showed that in my bone marrow there was active disease. If I recall correctly, 7% blasts. So the transplant was cancelled.

The decision about when to have the biopsy this time around is complicated because of the constraints of the clinical trial. If, like in April, I had an initial biopsy which showed complete remission this would render me ineligible for the trial, since it is specifically restricted to people with refractory AML over 55. If a week or two later a second biopsy showed that in fact I was refractory, then I would be back on the trial, but the schedule would be completely disrupted. Thus, we want to avoid doing the biopsy too early. But it also turns out that if

we wait the full four weeks -- until September 28 -- this will also disrupt the schedule for the trial since a requirement of the trial is that various tests must be within 30 days of the trial. In particular, the health tests which cleared the new perfect-match donor for the trial expire on the 28th. This means we need results from the biopsy by the 26th to be sure that I am randomized before the 28th, otherwise those tests would have to redone, which would throw everything off. So, we can't wait the full four weeks.

I was told by the local clinical trial coordinator that the latest date for the biopsy for which we could still get pathology results by the 26th was Monday the 24th, so that seemed to me to be the best date. Over the past few days several of the people involved in the study told me that the biopsy would indeed be on the 24th, but others reported that it would be on Friday the 21st. Finally, yesterday afternoon I was told definitively that it would be on Friday.

I didn't understand the rationale, after the April experience, for not having the biopsy as close to the 28th as possible. So, this morning, when the medical student who is always the first to see me in the morning came by, I suggested that the two of us do a mini-research project to see why the earlier date was picked. What I wanted to do was compare the relevant numbers from the peripheral blood tests at the time of the two biopsies after the April chemo, with the same numbers today. The relevant numbers were for the white blood cells, the neutrophils, and blasts as a % of WBC. Here are the results:

April 30, when the biopsy indicated a complete remission: WBC = .7 (normal is 3.9-11.2); ANC = 0; blasts = 0  
 May 14, when biopsy indicated refractory AML: WBC = .8; ANC = 260; blasts = 1% of WBC

September 19: WBC = 1.0; ANC = 0; blasts = 0

September 20: WBC = 2.9; ANC = 170; blasts = 43%

The September 20 results are pretty dramatic. The WBC is considerably higher than on May 14 (when the biopsy showed refractory AML), indicating that my marrow is producing white cells, and ANC count was roughly the same order of magnitude as in May. But the blast percentage today is very high at 48%. It is basically impossible to have that level of blasts in the peripheral blood without also having significant blasts in the bone marrow. Thus, the biopsy tomorrow will definitely confirm that I am refractory and thus still eligible for the clinical trial.

**2. Randomization.** This will happen immediately after the pathology reports are back from the biopsy. That should be on Monday or Tuesday. As I've said, there are two outcomes: the treatment group or the salvage group.

**3. Salvage group.** It will be really annoying to be randomized into the salvage group. This will mean that I will have to undergo another round of chemo of the sort I have just completed, basically doing what would have been done if there were no clinical trial: trying, once again, to get a robust remission. From a substantive point of view it would make more sense to treat the chemo cycle I just did as the salvage treatment -- i.e. I have just tried for a complete remission and failed. But the experimental protocol requires yet one more attempt. This should begin almost immediately and, I was told, would be the mildest of the chemo regimens approved for salvage groups in the study. This will delay my actually entering the treatment arm of the study until mid-November.



4. **Treatment group.** If I am randomized into the treatment group, the schedule should be the one attached below. I will begin the process on October 1 with what they call dosimetric dosing -- basically figuring out precisely what should be the radiation doses once the actual treatment begins. I will then enter the hospital on Thursday, October 11, and begin the 3-6 day isolation phase of the Iomab treatment on the 12th. This is called Day minus 13. Day zero, the "receive donor cells; transplant day!" is October 23. I am scheduled to stay in the hospital until sometime during the week of November 11. From then on out, basically, I will be in slow recovery, 6-12 months. That recovery process will begin by staying in Milwaukee in an apartment near the hospital for another 45-60 days, and then returning to Madison around the New Year.

So, that is how things stand now. I'm excited to be moving on to the main event.

## Comments

Your patience is commendable

—John Posner, September 20, 2018

You instruct to us the meaning of patience, which helps us very much as well.:-) Thank you for remaining so mindful and calm, that is so inspiring. Xoxox

—Isabelle F., September 20, 2018

Keeping my fingers crossed for you!

—Vicky Chang, September 21, 2018

## An interlude of meandering thoughts and photos

September 21, 2018





It is 6:30 in the morning on Friday, the 21st. I'm sitting in my room waiting for my breakfast. Later today I will have bone marrow biopsy #6. I'm kind of looking forward to it. It will be with a different practitioner than my previous painless biopsies, so it gives me a chance to see if my walking-through-the-jungle meditation is as effective as it has been. I see these biopsies as similar to an outdoors physical challenge like rock climbing or intense biking in hilly terrain: you know in advance that there may be moments that are uncomfortable, even painful, and you have good strategies to avoid the worst of those, but the very fact of those hazards is part of what makes the expedition an exciting challenge. I know it probably sounds weird to put a bone marrow biopsy in the same category as rock climbing, and of course in my heart of hearts a biopsy is not really just a longed for physical challenge: I would rather be about to go on a 50 mile bike ride in the hilly area west of Madison where I know that there will be hills in which my muscles will burn. But still, it is also not a pure mental contrivance of self-deception to play a classification game like this. I will report later how the challenge goes.

I do a lot of self-consciously using classification systems to make life easier. I often say that I am "coding" many of my experiences as a patient in the "interesting" column. I have my "silver lining" list for getting acute myeloid leukemia. There is nothing phony about that list: feeling more deeply connected to a web of people who care about me and who I deeply care about is a positive outcome. Writing my long letter to my grandchildren is a wonderful thing I am doing, and there is no way I could ever have carved out the time for that if I hadn't been able to clear everything else off my to-do list. Getting to really understand in a much deeper way the qualities of interactions between the caregivers at every level -- doctors, nurses, CNAs, techs, transporters -- and patients (i.e. me) would not have been possible without the lengthy stays I have had on this ward. I can even say, without this just being trying to sound clever, that if I survive this, then on balance my life has been

enriched by the experience of this illness. Saying this sort of thing gives me the reputation of being a Pollyanna. I'll accept the label so long as Pollyanna is seen as genuinely experiencing and embracing the "bright side of things" rather than just being in denial of the negative. I am not in denial. I fully understand that there is a fair chance that I will die as a result of my illness, and that deeply saddens me. I don't even forget that unhappy possibility when I focus on the positive experiences, but it shifts to being an out of focus feeling rather than the center of my life in the present moment.

Sometimes, of course, verbalizing a novel classification of a situation is way of being playful. The first photo below is the view from my room on the 7th floor of CFAC. The hospital is adding four floors, and the roof area immediately outside our window is a staging area for various things that get hoisted up to the actual worksites. So, what are the ways to think of this view? A worksite? A relatively unpleasant view compared to last April where we had a lovely view of a pond and trees? No: This is an intriguing Art Installation on the roof of the Museum of Modern Art by some famous artist. There are even fantastically well-designed, beautifully-crafted human automatons who wander about. MOMA is putting Marcia and me up in a full-service guest room where all of my meals are provided and the wonderful staff is doing everything they can to make my stay comfortable. And it is all free, paid for by Medicare, which strangely pays for stays in the MOMA penthouse guest room overlooking the rooftop sculpture installation.

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**Interruption -- Flash News:** The head of my hematology oncology team just dropped by to say that there is a change of plans: She does not want me to be discharged today as originally planned. My white cells and blasts have been rising rapidly, clearly indicating that I the active leukemia is back in force. Dr. Michaelis wants me to go directly to the clinical trial rather than have any interregnum, so if I am in the salvage group that will start immediately, and if I am in the treatment group, the dosimetric calibrations for the Iomab monoclonal antibodies Iodine-131 warheads will start sometime next week rather than waiting until October 1. So I will remain happily ensconced in my MOMA guest room with Marcia.

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A few photos:

1. *The work station I have set up in my room.* I have a nice full-size keyboard and mouse connected to my laptop. The internet and Wi-Fi in the hospital are terrific -- fast and reliable -- so I have no difficulty connecting via VPN to the Wisconsin server where I store my work files. I have an excellent Bluetooth speaker to play music from my iPod which plays my YouTube classical playlist. Right now I'm listening to a wonderful 3-hour album of Schubert Sonatas and Impromptus played by Claudio Arrau. I still find it remarkable that I can search for any piece of music I want and add it to my classical playlist and then play it whenever I like.

2. *Marcia and me sitting outside of the hospital on a warm weekend afternoon.* Because I have no functioning immune system, I avoid going out of the ward into the general hospital, even wearing a mask. There is no direct access to the outside from the 7th floor of CFAC, so that meant that I hadn't been outside for a couple of weeks. But last weekend, since the entrance to CFAC was closed and so there would be no one in the main lobby, Marcia and I went down to the entrance and ventured outside. It was hot and sunny, and I am supposed to stay out of the sun, so we didn't go for a walk, but found a nice piece of shade in front of the building in which to sit

and feel the warm breeze.

3. *Photos of me from Kindergarten through sixth grade.* I just wrote the section of my letter to my grandchildren about elementary school and found, in a scrapbook I made in 1959, a set of classroom photos from those years. I took a photo of each of those photos and then cropped them to isolate the photos of me from age 5 to age 12.

## Photos





## Comments



OK Erik, looks like it's off to the races now; wishing you best of luck in the clinical trial!

—Jonathan Patz, September 21, 2018

Thinking of you and Marcia and sending love and best wishes.

—Judith Leavitt, September 21, 2018

I love watching processes of creation -- art, music, cooking, building. Collaboration, individual effort, knowledge, experience, technology, ancient practice and newest approaches, all come together. So glad the universe has provided a fascinating and on-going example adjacent to your room. And fingers crossed that the sound insulation on those windows is pretty good!

—Margaret Vitullo, September 22, 2018

Eriki - I LOVE the pic of you and Marcia. I am sending you love and healing thoughts. I read all of your posts and I'm cheering for you. XXOO.

—Jennifer Wilgocki, September 22, 2018

Erik--Have been shy about posting because we don't know each other well, though we are connected by our immense love and respect for Marcia Kahn and her family. John and I have followed your postings with great concern and with admiration for your courage and your expressiveness. And I am awed by how well you can explain your disease. When I joined the Cancer Club, I never grasped much more than I had a "run of the mill"--and potentially lethal breast cancer. Scientific concepts, and plain old anatomy, have always been abstract to me. Oh, and it was 28 years since I was initiated . I think all of us who joined--excuse the phrasing-, like to hear from people who went through treatment, physical and emotional exhaustion a long time ago. I believe you will be one of those people. Loving thoughts, Eve and John

—Eve Silberman, September 22, 2018

I love the pics! Sending big hugs

—Tom Malleson, September 22, 2018

I cannot emphasize enough that your beautiful smile and remarkable serenity in the face of a challenging process such as this are so inspiring. So much love!

—Masoud Movahed, September 22, 2018

## The mystery of fever spikes

*September 22, 2018*

Yesterday morning I felt terrific. I was symptom free except for a weird bright red circular patch, about the size of a dime, on the side of my lower calf. This had not been there during the day before. I had first noticed it after my shower the previous evening. It was quite tender to the touch. I pointed it out to the attending doctor, who put in an order for the dermatology team to look at it. They came in the late afternoon and did two biopsies. The only painful part was the sting of the lidacane numbing shot. I was pretty tired. It was a full day of biopsies -- first the bone marrow and then the skin. But I still felt fine.

Then my temperature began to slowly rise. For weeks it had been in the 97.6-98.6 range. It started at 99.1, then 99.5, then 100.1, finally crossing the threshold of 100.4 (38 C) which is used as the criterion for trying to figure out the source of a fever. New antibiotics were added to my regimen. A chest x-ray was ordered (fortunately at my bedside). They were waiting for results from the skin biopsies, which included getting a bacterial culture. My temp continued to rise, reaching 103.5 (39.7 C). I felt totally dreadful. Even though the doctors were interested in how high the fever would go, they decided to give me 600 mg of Tylenol. While all this was going on, another symptom appeared: when I got out of bed and put weight on my feet, I felt sharp, intense shooting pains on the back of my calves. This was on both legs and so did not seem directly related to the bright red florid lesion on my left leg. The leg pain was sufficiently intense to make me unsteady. The intensity abated after a few minutes.

The Tylenol significantly reduced the fever. I sweated profusely when the fever broke; I was hopeful that maybe the underlying condition had was resolving. The temperature bottomed out at 99 F and change, and then started rising again once the Tylenol had worn off. Phooey. We went through this cycle again: Tylenol, temperature drop that made it possible to sleep, then a bit longer period with the temp below the panic threshold, and then a slow rise. Right now it is 102.6 F (39.2C). I don't feel crummy yet, so the doctors want to see where the fever goes. Now 102.7F. But I still don't feel crummy, so we'll see what happens. My taste buds, which had been behaving much better in the past week have once again decided to give almost everything an unappealing taste. The result is that now, late in the afternoon, I am very hungry since I haven't eaten much, but nothing seems palatable. This is clearly the work of the EVIL mutation in its trickster manifestation: determined to annoy me as much as possible.

The doctors do not yet have this fever nailed down. The main sentiment is that this is probably a Leukemia Fever, caused directly by the disease rather than by an infection. My white blood cell count went from zero to 6900 in four days, and along with that my blasts have also risen rapidly in recent days -- from undetectable four days ago, to 48% of my white blood cells today. When my White Cell Count hits 10,000 they will put me on a drug to suppress them, Hydroxyurea or something similar, to help stabilize my condition for the clinical trial.

Monday will probably be Randomization Day. As soon as I know anything, I will post it.

## Comments

I am very sorry to hear about the resurfacing of symptoms like fever and taste buds issue! Here is hope that they are gone very soon. Sending you big hugs and much love!!

—Masoud Movahed, September 22, 2018

Sending healing vibes your way!

—Annabel Ipsen, September 22, 2018

Holding you in the Light, Erik.

—Margaret Vitullo, September 22, 2018

Sending so much love from Brooklyn. I am sorry to hear about this bumpy moment and I hope it passes quickly. I am ever impressed and inspired by your spirit of adventure throughout. Much love, Amelie

—Amelie Davidson, September 23, 2018

AAArrrgghhhh! I read yesterday and today's comments one right after the other. Kind of illustrates the ups and downs. LOVE the photos - of the view, you and Marcia :- ) :- ) and your school photos, and - yes - your indomitable Pollyannaishness (the right kind). And then I get really mad at this \$\$\$&\$!! disease. But you are going to get the best of it!

—Mary Jo Maynes, September 23, 2018

## Upsanddownsandupsanddownsandups

September 23, 2018

I woke up this morning feeling fresh, full of energy, no burning aches in my leg, no chills, nothing indicating a fever. I had gotten a transfusion at 5:00 a.m. because my hemoglobin count had dipped below 7. So, I planned to write an update full of vim & vigor, proclaiming the End of the Spiking Fever Drama. Then Marcia reminded me that I had been given 650 mg of Tylenol at 4:00 since I had a fever at that point of 102.6, and you can't get a transfusion if you have a temperature above 100.4. The Tylenol had knocked the fever down to 100.3 -- below the "you've a fever threshold" -- so I got the transfusion. At 7:00 a.m. when my vitals were measured my temp was even lower, 98.6. Whoppie, thought I, this episode in the drama is over. Alas, I had to wait until 10 a.m.

before I would get a true temperature reading when the effects of the Tylenol had dissipated.

Joel Rogers came by for his weekly visit about 8:30. Still feeling pretty good. Let's go for a walk in the corridors, I suggested. We have been having weekly Sunday walks for around 30 years. That's part of the reason why Joel has been doing the trek to Milwaukee every week -- to keep the tradition alive even if we haven't been walking. But today I felt we could do a few of the 1/8 mile laps around the two connected corridors of 7CFAC. Off we went. Becky called on Facetime after we had almost completed two laps. Vernon wanted to talk to Dadoo. So we stopped and went into the Meditation Room for a lovely Vernie-Dadoo exchange. Talk of important things like his new underwear with monkeys and the expedition to Old City they were about to do on the train (SEPTA). When we were done and I stood up I felt I was clearly fading, so we went back to the room. A little after 10, I got a new temperature reading: 102.3. I didn't feel anywhere near as miserable as yesterday. My legs were fine -- I could walk without difficulty and there were no shooting pains. Mostly, I just felt tired, so I crawled into bed and went to sleep. I was asked if I wanted more Tylenol and I said that so long as I only felt tired rather than crummy from the fever, I would hold off in order to better track the fever.

Gradually since then the temperature has trended down. The last few readings have been around 100.2, below the threshold for official doctorly concern. So, I think this episode in the narrative of my illness is finally coming to a quiet ending.

## Comments

No matter how frustrating the upsanddownsandupsanddownsandups on the way, you will defeat this with your unflagging fortitude, just how you defeated other challenges in the past. Sending you big hugs and much love!!

—Masoud Movahed, September 23, 2018

Hi, Erik,

I am following your ups and downs and hoping and even (in rare moments, for me) praying for you. I also very much appreciate your observations, musings, analyses, and positive reframings of your experiences, and very much relate to how you described the pleasure of meaningful work and meaningful conversations with others via this blog. Your words articulated well my feelings about the blogging I did during my cancer treatment. I especially love the sentence "It is an important part of the pleasure of this writing project that we are together as I write." What a wonderful way to think about the relationship between writer and reader! And it moved me to write to say yes, I am with you.

Your cancer is so much more life-threatening than mine has so far turned out to be (and than it felt while I was in treatment for it), and your treatment is longer and more grueling than mine was. Yet, I feel there is a lot of similarity in your approach to it – as an adventure, a challenge, an opportunity to learn, in addition to a set of unpleasant, painful, and scary experiences. This is both validating and reassuring that if I were to develop the much more dangerous metastatic form of the disease (or some other illness), I would also be able to maintain my mostly positive outlook.



This brings me to one of the main reasons I have felt moved to write you a longer note -- RECLAIMING POLLYANNA! Although "being a Pollyanna" is a dismissive epithet in our culture, I believe this usage is a deep disservice to the power of positive thinking, and a misconstrual of the original Pollyanna story. When I actually watched the Disney movie Pollyanna with Hayley Mills a few years ago, I realized she was a true hero. She transformed the lives of many people around her, indeed the culture of her whole village, by getting them to shift their negative attitudes and behaviors. And (spoiler alert!) when she was severely injured and lost her own sense of hope, they all came to help her regain it. The original creator of Pollyanna was a pioneer of positive psychology well before her time.

Another reason I've wanted to make time for a thoughtful response to your blog recently was your thoughts about the differences between scientific discoveries and artistic creations, and "the messy way" sociology does both. I remember the relief and pleasure I felt when I encountered this explanation of why we still have to read Durkheim and Marx during my Sociological Theory Prelim studies (was it Giddens? Clearly I would fail the prelim if I took it again today!). I have quoted your idea about "With Einstein we would still eventually have relativity theory, but without Beethoven there is no Beethoven" in at least two social conversations since reading it the other day (with attribution!) so maybe this too will percolate outward further to change people's beliefs, and you "accomplished something" bigger than you thought that day!

Your musings about this also feel relevant to my motivations in my current new endeavor, another writing project. It is a sociological science fiction novel about a sandwich generation academic who believes that time is actually speeding up, and who goes on a scientific and spiritual quest to save herself, her family, and the world. Along the way she will encounter a number of small "real utopias" like the one you describe at Froedert's CFAC, where enclaves create alternatives to the "harsh efficiency treatment of time." Thanks for sharing those observations and analysis as well!

Much love, and hoping you get in the treatment rather than the salvage group today!!

Becca Krantz

—Becca Krantz, September 24, 2018

Hi Erik

I have been traveling for the past month and am back now in Madison. For a month or so. I gather that you are now in Milwaukee, right? Big hug from Irene and me. Please let us know when you are back in madison

—Boaventura Santos, September 24, 2018

## (non)Randomization Day

September 24, 2018



[There is some very strange issue in formatting for this posting which I cannot seem to correct -- lots of big white spaces between many of the paragraphs. I'll call Caringbridge and see if they can fix it tomorrow. EOW]

Today was SUPPOSED TO BE Randomization Day. The resident on her rounds this morning confirmed that this is what she has been told. As soon as the biopsy results arrive, the little gray button gets pushed, the algorithm does its thing, and spits out the result.

It turns out that this information was not correct. The preliminary biopsy results can unambiguously show refractory AML, and still this is not sufficient to trigger randomization. Some other more refined results are needed. We just found out (4pm) that this is the case for me: the preliminary biopsy results are unambiguous, but some other results are needed to satisfy the protocol for the study.

Thus: another delay. This is certainly frustrating, intensified by the recent history of last minute cancellations of randomization. This is not a cancellation, but still a disappointment.

Half an hour later (4:30) the attending doctor came in and gave us a little more information, but really not

enough. He suggested that the issue was some missing eligibility information concerning the donor, not the biopsy. This was "just" paperwork that needed to be signed off on, and "should" be resolved by tomorrow. So the randomization will "probably" happen tomorrow. All very unsettling.

What follows is an extended blog posting that I wrote during the day today as we waited for the randomization news.

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I thought that while waiting I would keep a real time diary of the day's happenings.

6:45 a.m. Woke up pretty refreshed and energetic. Had a platelet transfusion at 4:00 a.m., but no new red cells. I was started on Hydroxyurea last night – an oral chemo to knock down white blood cells because mine were rising so rapidly. This also has effects on other blood components, so daily transfusions are likely to happen. My hemoglobin had been significantly reduced since yesterday, but not below the magic threshold for transfusion. When I stepped out of bed I initially felt in my left ankle and lower calf the shooting pains from the weekend, but this dissipated right way. Something to tell the doctors.

7:00 a.m. Set up my workstation. Decide to begin my morning music with a Horowitz recording Shubert and Schuman piano sonatas that contains Schuman's "Scenes from Childhood," which I love. Ordered breakfast: omelet with triple spinach and triple tomatoes; two cream of wheats; sparkling water and cranberry juice; a bagel not put under the dome, but just on a plate on the side so it won't arrive soggy. I can get it retoasted in the ward. I know the omelet will be rubbery – overcooked. But on a bagel it becomes an acceptable breakfast sandwich. The cream of wheat has been a reliable item through my fickle taste buds: with a little syrup and 2% milk, it is quite nice.

7:15 a.m. Marcia is up and turns on the coffee. Having our own coffee machine is fantastic – good, strong coffee in the morning. Read and answered emails.

7:30 a.m. My vitals are taken. Temperature is 98.6. The fever episode is over. Breakfast arrives and displaces my laptop from my workstation.

8:00 a.m. The nurse comes in. Time for morning meds and my self-administered blood thinner injection. The injection is really no big deal. The only challenge is finding a spot in my belly fat that is free of previous injections. The number of pills keeps mounting, so I can't just pop the whole lot in at once and gulp them down; I have to divide them into three groups, I've attached a photo of all the pills.

8:30 a.m. The wonderful resident doctor comes in on her rounds. And asks how I am. I tell her about the shooting pains and that now they are gone. She looks at the place where the biopsy of the original lesion was taken. There is just a bandaid on it today. Yesterday the bandaid was changed. Until there was no redness outside of the perimeter of the bandaid; today there was a large, angry red inflammation extending well beyond the bandaid. I told the doctor that this definitely wasn't there last night when I took my shower. We surely would have noticed it when I dried off with Marcia's help, especially when we did the CHG (anti-biotic ) wipes on my legs after drying off. She looked closely. She commented that it certainly looked like a skin infection, but that I was receiving pretty strong antibiotics that covered a very wide range of sources for such infections, and so far there are only negative results from the skin biopsies on Friday. She will alert Dermatology; they will come back sometime today to look at it.

9:00 a.m. finish the interrupted breakfast. Catch up on my real time diary, which I guess is almost-real time since there will inevitably be interruptions in which I can't write down what just happened.

10:15 a.m. I felt sleepy and decided a rest was needed. Feel almost instantly to sleep, and slept until 11.

11:00 a.m. The attending doctor from the hematology team this week, Dr. Guru, came by. He looked at the red inflammation and confirmed that Dermatology needed to look at it. He also said he would have Infectious Diseases come by. Marcia asked him what he thought about the likelihood of actually getting randomized. He replied, "over 80%". I quipped "87.2%. Well, it *is* over 80%, and not 90%.

11:30 a.m. Marcia goes to get herself some breakfast from the Patio Café, and also something later for lunch and dinner. Mahler's 4th symphony is merrily playing on my playlist.

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**An interlude outside of today's description of events**

I have finally begun to lose hair in abundance. Last night I gathered up what had fallen out when I ran my fingers through my hair and took a photo (attached). What a nice little creature – the very rare, elusive, erikifuzzball (*erikus fuzzballus americanus*). As far as I know this is the first one ever photographed.

As you can see from the other three photos attached, I still have hair on my head, but if you take a photo backlit, the shape of the underlying bald pate is revealed. I don't think it is actually so pointy at the top; that is probably the result of the distortions of selfies and backlighting. And if the light is just right, the remaining frizziness turns into a Halo.

Here is my plan for my hair: Once I know for sure that I am in the treatment group and bound for a transplant, I will shave off the remnants of my hair. I have always seen my hair as part of what I suppose one would call my "signature look," and I have to admit that as I've grown older and many male colleagues go bald, a source of undeserved vanity. Vanity is a sin, right? A minor sin, but a sin nonetheless. I've been curious what I would look like bald, but too vain (alas) to just cut off my locks to check it out. So, this is my opportunity. What's more, the transplant provides a nice symbolic occasion to begin bald: The actual day of the transplant is called Day zero; the fourteen days of procedures leading up to that are given negative numbers beginning with minus 14. Day zero is also referred to as Rebirth. OK, I'll accept the metaphor. If I am new baby on day zero, I will be a bald baby, and a bald baby was surely bald 14 days before birth.

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Back to the real time diary.

1:25 p.m Marcia and I are going for our daily hallway walk.

2:05 p.m. Back from the walk. 8 laps. One mile. My feet are a little weird, mostly I think because they are a bit swollen, but perhaps this is what is called peripheral neuropathy, but nothing serious. Periodic comments from passing nurses and others: "love birds," "You are so cute."

2:25 p.m. Ordered lunch from the dining room menu (rather than regular dining service menu). French onion soup and spinach ravioli. Sounds good on paper. I hope my taste buds cooperate.

2:30 p.m. I'll work on my letter to my grandchildren until lunch arrives.

2:45 p.m. Infectious Diseases arrives. [I think this is singular, because ID is the name of a specific service, and so it is the same as saying Cardiology arrives. And the diseases themselves, in any case, did not arrive.] The doc examines my leg. She feels this is almost certainly an infection even though I'm getting a lot of potent anti-biotics. She says I need to elevate my leg during the day to reduce the swelling, since the swelling reduces the effectiveness of the anti-biotics. She makes a small change in main antibiotic being used, vancomycin, to something that is pretty similar but has a somewhat broader spectrum. Vancomycin is the first line drug for this sort of situation because the alternative is much more expensive, but she thinks it is justified making the switch.

3:00 pm. Lunch arrives. Tolerable – I could eat most of it.

3:15 p.m. After lunch we discuss with the nurse how best to elevate my legs. I say the main problem is that I can't really use the laptop in bed. She suggests that I reorganize my workstation so that my legs could be propped up on the couch. "I thought they had to be above my heart," I said. "That would be even better," she replied, "but you'll get much of the benefit by just elevating them." So we organized my workstation. Peachy.

4:02 p.m. A resident from the hematology team just dropped by to say that they have received the preliminary results of the biopsy which show refractory AML in the bone marrow, but they are waiting for a few other results "behind the scenes" before they can actually do the randomization. The randomization will be tomorrow, September 25.

4:30 p.m. The attending physician came by to talk to us about the situation. He had talked to Dr. Michaelis who was in close communication with the head of the study team and others. What he had to say was not very reassuring under the circumstances. The randomization will "probably" occur tomorrow. There are still a few "eligibility" criteria for which paperwork needs to be "signed off". We asked if these concerned me or the biopsy. No, they concerned the donor he said. We were surprised -- no, we were shocked. We had definitely been told that the donor had been completely cleared. What was the missing paperwork? This is exactly what we were told last time -- the head doctor of the donor center had not yet signed off on all the paperwork. At the last possible moment we were told that the donor had a clearable condition.

5:00 p.m. Dermatology arrives to look at my inflamed lesion on my ankle. He's not worried about it and agrees with Infectious Diseases that it is an infection. The antibiotics will clear it up. He is confident about that. But I need to keep my leg elevated.

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Enough of the time diary. We're now waiting for more real information about the specifics of the missing eligibility criteria. I'll post this blog now and a further update tomorrow.

## Photos













## Comments

Your face stands out without as much hair - easier to notice your handsome face which is filled with sensitivity and strength. Of course the hair is wonderful - looking forward to it growing back. :) Jody

—Jody Whelden, September 24, 2018

Love you, Eriki!!

—Lisa Baker, September 24, 2018

I think the hair/head pix do confirm your status as a pointy-headed intellectual! Snags and snafus can be super frustrating! Your good humor seems to be carrying you through, which is lovely to see!

—Myra Ferree, September 24, 2018

Your beautiful smile in the photo, despite the frustrating delays in the process, shines my day and warms my heart. So much love!

—Masoud Movahed, September 25, 2018

I think your new look is quite captivating, it has a surprised expression. I'm so sorry about all the delays...medical limbo is the pits. I hope clarification is nigh!

Sending love from Marseille,  
Sonia

—Sonia Baku, September 25, 2018

## Flash News Report: FedEx screws up Human Mouse antibodies sample

September 25, 2018

We now know what happened. One of the eligibility issues for Me -- NOT the donor -- is that I have no human mouse antibodies. Those antibodies occur when someone has had a previous therapy that involved mouse cells. If you have those antibodies, then the Iomab treatment won't work, since it does use mouse cells. I passed this screening 6 weeks ago: no human mouse antibodies. The study protocol requires that the assay of these antibodies be within 28 days of the beginning of the treatment. So, a new sample was sent to the relevant lab a week ago to get the test for these weird antibodies. FedEx screwed up and the sample took too long to get to the lab, therefore degrading the sample. When the sample came back yesterday, the sponsor head of the overall clinical trial rejected the results and said we had to redo it. Thus the delay. A new sample was drawn this morning and sent off with instructions for expedited delivery. The test results should come back by late Wednesday or early Thursday; and then randomization should take place immediately thereafter. There are no other missing pieces of the puzzle.

Marcia and my relief was instant once we knew that this had nothing to do with donor eligibility. And there is zero possibility that somehow mouse antibodies snuck into my body during the last six weeks. So Thursday (or possibly late Wednesday) is the new randomization date.

## Comments

Well that's weird! But, as you said, a relief!

—Mary Jo Maynes, September 25, 2018

What a relief!! Looking forward to more good news - so much love!

—Masoud Movahed, September 25, 2018

Phew. Oh what an odyssey this is with human error, fed ex error, emotional and physical roller coaster but always at your side- your steady co-pilot Marcia K Wright!!!! Sending love to you both.

—Kathy Cole-Kelly, September 25, 2018

Excellent news! Full steam ahead.

—Janeen Baxter, September 25, 2018

## on perkiness and blog posts

September 26, 2018

Someone asked my good friend Gay Seidman whether I was always as perky as I seemed to be in the blog posts. Part what is happening is a selection bias: when I really feel lousy, I rarely write. Today is an exception: I feel completely depleted and unperky; I have a 102.5 F fever which Tylenol has only reduce to 101.5; and I am coughing almost continuously (dry, unproductive superficial cough). And to top it off, my taste buds are back to their narrowest range of palatability. Basically, the only things I can eat are semi-liquids. So my diet yesterday was cream of wheat, a bunch of puddings, tomato juice, lots of skim milk. In the middle of the night I had more tapioca pudding. It wouldn't be so bad if Marcia could make me her fabulous smoothies, but she left the necessary equipment at home someone is bring it here today. Feeling this way, I would not normally write anything, but I thought it might be worthwhile to address the issue of my apparent super-human perkiness. I don't feign perkiness when I write a blog post; but I only write them when I'm above a minimal level.

There is no news to report on the upcoming Randomization. As soon as I hear anything, I will post it.

## Comments

Ah! Sharp methodological clarification for those of us who are interested both in your frame of mind AND in the various genres of personal narratives. Sorry that you are not feeling perky, but happy that you are as clear-headed about it as usual!

—Mary Jo Maynes, September 26, 2018

Hope the smoothie comes soon! Hugs, Eve and John

—Eve Silberman, September 26, 2018

## Randomized to Treatment!!!

*September 26, 2018*

I just found out that I have been randomized into the treatment branch of the clinical trial. All of the action begins on Monday with various imaging procedures and then the dosimetric dose study starting on Tuesday. The episode of isolation begins on Friday the 12th, and the day when I receive the donor bone marrow stem cells -- Day zero, my rebirthday -- is October 23.

I feel so relieved -- I'm ready for the Main Event.

## Comments

Great news!

—Sarah Siskind, September 26, 2018

Thrilled for you both!!!!!!

—Kathy Cole-Kelly, September 26, 2018

Great!

—Stefan Svallfors, September 26, 2018

Words cannot express what I feel.

—Dan Hausman, September 26, 2018

Such welcome news - finally!

—Cathy Loeb, September 26, 2018

Wonderful news, Erik! I have never wanted so much for a coin to come up heads.

—David Griffeath, September 26, 2018

Fantastic!!!

—Debra Satz, September 26, 2018

Hooray!!

The message we've all been waiting for!!

—Mary Jo Maynes, September 26, 2018

That's just excellent news, Erik!!!

—Hillel Steiner, September 26, 2018

This is amazing news! I am feeling jubilant - Love, love, love!

—Masoud Movahed, September 26, 2018

Mazel Tov!!! and all best for a relatively easy course and successful outcome!!

—Judith Leavitt, September 26, 2018

This is such great news! I can't stop smiling. Much love

—jeannette golden, September 26, 2018

Fanf\*\*\*ingtastic!!

—Joel Rogers, September 26, 2018

Erica sends her regards!

—Stefan Svallfors, September 26, 2018

Oh, what great news!!!

—Betseygail Rand, September 26, 2018

Oh Wric! I'm so glad!

—Susan Davidson, September 26, 2018

A truly exciting moment in your treatment, Erik. Best of luck with what's to come.  
It was wonderful to Skype with you from Madison last week. We are all pulling for you.

—vern baxter, September 26, 2018

Wonferful! I cant say it better than all your friends, but need to say it too. All the stars are aligned now.  
Shouting it out all around here in Paris!!! Xox

—Isabelle F., September 26, 2018

That is GREAT news. What good luck!

—elliott sober, September 26, 2018

Wonderful!!! Great news.

xxx

—Janeen Baxter, September 26, 2018

Super Hurrah! We are all looking forward to your rebirthday

—Myra Ferree, September 26, 2018

Super GREAT news!!! So, so happy!! Sending you big hugs from Argentina!

—Valeria Galetto, September 26, 2018

Rik,  
Along with what your many friends and relatives have written in such varied voices, this East-coast rupturalist  
breathed deeply and shed a few tears of relief. Yes, let the main event begin!  
Wally

—Wallly Rosenthal, September 26, 2018

Fantastic to hear, Erik! I wish you all the best of luck in the next chapter!

—Eli Smeplass, September 27, 2018

Eriki - the title of your post alone made my heart jump. I am so excited. I am sending you and Marcia my love.

—Jennifer Wilgocki, September 27, 2018

Great news!!! All the best for the next stage!

—Emanuel Ubert, September 27, 2018

FANTASTIC!!!!

—Gay Seidman, September 27, 2018

## "Do you have any other symptoms besides happiness?"

September 27, 2018



The attending physician came in today as usual, to see how I was doing, to discuss treatments and plans. "I feel free of symptoms," I said. The fever is gone. The coughing virtually gone. I'm not even tired. Happy as a clam. We discussed the upcoming shift from the hemonc team to the transplant team. He assured me that would go smoothly. Then he said to wrap things up: "Do you have any other symptoms besides happiness?"

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## A Dream last night

I'm sitting outside, in a high-backed old-fashioned chair. It is spring, a gorgeous beautiful spring day. Safira and Vernie are running towards me. They take my hands, Vernie on the right, Safira on the left: "Come with us Daado, come with us Daado." They are nine or ten years old; and at the same time, they are three years old. We walk holding hands down a path. Gentle woods on either side. We come to a open glade. Butterflies, birds singing, sunny sky. And there ahead is Uncle Remus singing:

Zip-a-dee-doo-dah, zip-a-dee-ay  
 My, oh, my, what a wonderful day  
 Plenty of sunshine headin' my way  
 Zip-a-dee-doo-dah, zip-a-dee-ay!

Mister Bluebird's on my shoulder  
 It's the truth, it's "actch'll"  
 Everything is "satisfactch'll"

Zip-a-dee-doo-dah, zip-a-dee-ay  
 Wonderful feeling, wonderful day!  
 That's it. A happy dream filled with promise for the future, with no shadow of gloom.

---

Before the randomization occurred, I said on September 24, that if I were randomized into the treatment round, I would then cut off my remaining hair in honor of the occasion. Well, today was haircut day. Below are before & after photos, and the last possible photo of an erikifuzzball. The creature has now been declared extinct.

## Photos





## Comments

Beautiful

—*Sarah Siskind, September 27, 2018*

Handsome dude!!!!!! Much love!!!

—*Kathy Cole-Kelly, September 27, 2018*

Gorgeous!

—*Devah Pager, September 27, 2018*

Love the look - and the guy.

—*Cathy Loeb, September 27, 2018*

You do realize I didn't recognize your photo, right? But the happiness story is DEFINITELY you, Eriki!

—*Gay Seidman, September 27, 2018*

Excellent haircut; a stylish and distinguished look of a prominent 21st-century public intellectual. You look so much younger, and, I agree with Marcia, so adorable.

—*Mansoor moaddel, September 27, 2018*

I don't know - a lot more hipster of a look than I'm used to!

—*Mary Jo Maynes, September 27, 2018*

I don't know if it's the happiness or the haircut, but you look 10 years younger with the hip bald top.

—*Myra Ferree, September 27, 2018*

You look so adorable, dear Erik! So much love, to you and Marcia!

—*Masoud Movahed, September 27, 2018*

You definitely look younger! You should stick with this style and hair stylist.?

—Janeen Baxter, September 28, 2018

That was my first thought too!

—Marianne Ahrne, September 28, 2018

Wow, nice! I want to see a pic with glasses on now. I bet you look a bit Burawoyish!

—Rodolfo Elbert, September 28, 2018

Agh! I love you guys! Xoxox

—Heather Crowley, September 28, 2018

You look ready to kick ass Erik!

—Adam Szetela, September 30, 2018

If you come out of this a Foucauldian, I will buy you a leather jacket!

[https://www.google.com/search?q=michel+foucault&tbm=isch&tbs=simg:CAQSnwEJpefIrwRgaOcakwELEKjU2AQaDagXCD0IQggUCAAIawwLELCMpwgaYgpgCAMSKLIZtRmxGc8OyA7eDt8O3Q7NdrYZ7STbLc46xS7qP-wkojrrP8cu7zoaMGR\\_18BkB8nB-fPWHCINyec-4lWFekSVCrowuzdYJa3D0DHPIEo99EhBr9wQV32aCLSAEDAsQjq7-CBoKCggIARIEXTH41Aw&sa=X&ved=0ahUKEwjp2tr18-PdAhVD5YMKHa8mA4oQwg4IKigA&biw=1366&bih=631](https://www.google.com/search?q=michel+foucault&tbm=isch&tbs=simg:CAQSnwEJpefIrwRgaOcakwELEKjU2AQaDagXCD0IQggUCAAIawwLELCMpwgaYgpgCAMSKLIZtRmxGc8OyA7eDt8O3Q7NdrYZ7STbLc46xS7qP-wkojrrP8cu7zoaMGR_18BkB8nB-fPWHCINyec-4lWFekSVCrowuzdYJa3D0DHPIEo99EhBr9wQV32aCLSAEDAsQjq7-CBoKCggIARIEXTH41Aw&sa=X&ved=0ahUKEwjp2tr18-PdAhVD5YMKHa8mA4oQwg4IKigA&biw=1366&bih=631)

—Adam Szetela, September 30, 2018

Adding my voice to the chorus of you look younger! I'm imagining you as a rockstar, tatted up and wearing a bomber jacket and combat boots, ready to take on the world!

—Josh Wright, October 10, 2018

## mini-blog: Informational Update for visits & a few other things

September 28, 2018

I now know pretty definitively the details of the schedule of treatments for the upcoming period, so I can list

days were visits will be fine.

### **Days when visits are OK**

September: 9/29-30

October: 10/4-10, and 10/24 for the rest of the month

Please let me know when you would like to come so I can avoid having too many people on a single day.

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I'm adjusting to my new look. Every time I look in a mirror I don't recognize the face looking back at me. Very strange.

---

I remain free of all symptoms of any importance. A nice little break from feeling sick.

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Marcia and I started watching Sneaky Pete. Pretty entertaining. I'm listening to Michael Ondaatje's book Warlight. Extremely interesting, but I am not yet sure what it is "about". I tend to fall asleep after ten minutes or so, then wake up much later to turn it off, and so have to figure out what I last heard when I want to continue listening. Not the best way to listen to a literary novel.

## **Comments**

Hi Erik,

I'm on sabbatical, away a lot. I'll be in Madison Oct 8-10, can visit on any of those days. Please let me know what works for you.

I've been following, I'm in awe of your strength.

Big hugs, Joan

*—Joan Fujimura, September 28, 2018*

Hi Erik.

How about updating your Caring Bridge picture to the new look?

xo, d.

*—David Griffeath, September 28, 2018*



## The Beauty of Pills

*September 30, 2018*



It has been a slow news day here in 7CFAC14. Pretty much symptom free aside from fatigue and scrambled taste buds. Took two long naps to deal with the first, and drank a variety of drinks to deal with the latter, since there seems to be a fairly broad range of things that are pleasant to drink even if almost no solid food is palatable: coffee; V8 vegetable juice (4 six ounce cans); ensure-based chocolate shake fortified with protein and ice cream (two 22oz drinks so far); a strawberry smoothie made by Marcia; a mango smoothie with extra protein brought by a student; a strawberry ensure; two 8 ounce skim milks. That's my cuisine for the day.

Below is a photo of my cornucopia of morning pills. The isolated pill at the bottom is B12, which stinks so much that I segregate it from the others. At the top is the shot of blood thinner I stick in my belly as a special treat. It's actually no big deal. The four pink & green capsules are the most important: Hydroxyurea, a chemo drug that is keeping my leukemia under control in this run-up to the transplant. All the other pills are meant to deal with this and that or something else: anti-fungal, anti-viral, anti-bacterial, anti-constipation. Lots of antis. Taken together, it is a pretty picture.

Tomorrow I am officially handed over from the hematology-oncology team to the Bone Marrow Transplant team. I will have some imagining in nuclear medicine to create baseline data, but no treatments. Then on Tuesday, October 2, the real action begins: the dosimetric study to determine the level of dosage Iodine-131 for

the treatment itself. I'm told this means 6 hours in a single room in nuclear medicine. I'll blog the details at the end of that day.

## Comments

Love "symptom-free." May it continue. xo

—Cathy Loeb, September 30, 2018

## Day 1 in lomab-B clinical trial

October 1, 2018



Today I was officially handed off from the hematology-oncology team to the transplant team. The first event was a trip to nuclear medicine for some baseline images of my torso. This meant being strapped down onto a sliding table and then slid into an apparatus which I think was a PET scan, but I'm not sure. The only problem with having my arms at my side tightly strapped to my body is that my nose began to itch. I'm sure this was Loki's doing: what is more annoying than an itch you cannot scratch. But little did Loki know that as part of my meditation practice I have learned how to dissolve pesky itches without scratching them: what you do is focus all of your attention on the itch and then when you exhale through your mouth you pretend that you are exhaling through the itch, and presto -- it disappears after two or three breaths. I successfully got rid of one nose itch, one



ear itch, and one neck itch while strapped down in the PET-scan machine.

Tomorrow is the much bigger deal dosimetric dosing study starting at 7:30 a.m. and lasting about six hours. For this I will get a sub-therapeutic dose of the radioactive monoclonal antibodies that I will receive on October 12 when I go into the lead shielded isolation room. The infusion will take three and a half hours, and then they will do a series of images to watch the diffusion of the radioactivity. This will be a strange kind of radiological image, because all of the radiation will come from inside of me.

The transporter came to my room to get me for these scans at the top of the 8th inning in the Brewers-Cubs one-game tie breaker for the championship of the central division of the National League. I was watching it was we wended our way down the corridors. At every work station, everyone was watching the game. By the time I got down to nuclear medicine, the Brewers were ahead 3-1. By the time I had gotten out, they had won. The Cubs now have to play the Colorado Rockies in the wild card game to claim the fourth spot in the playoffs. I hope they win. If they do, then they will play a best of 5 series with the Brewers. That will be a lot of fun in the hospital for sure.

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I may have already mentioned this: My niece, Betsygail, has been sending me a present every week. When her Mom (my sister) had esophageal cancer a decade or so ago, I sent her a little present every week so that, as I put it, she would have some reason to regret the end of treatments. Well, BG is following suit. This week she sent me a magic wand (see photo below). I thought some of you might enjoy the email I sent back to her:

I opened the package and there it was, what I have longed for: a magic wand. I shook it. I watched its beautiful stars tumble up, surely a magical property. I pointed it at a pillow and said “Holy Moly Kalamazoo, turn that pillow into a tiny rhinoceros or two”. The wand started laughing. I put my ear next to it. “What is this stupid Holy Moly Kalamazoo? That’s no way to address a magic wand.” “What should I say?” “Why don’t you try something dignified like Tihslub Tihslub?”

OK, I’ll try it: “Tihslub Tihslub, turn my pillow into tiny 1 inch rhinoceroses.” With a puff of mist, a tiny rhino, no bigger than the first joint on your thumb, poked its head out of the pillow case and started romping around on the bed. Then another. And another. Soon there were two or three hundred tiny rhinos gallivanting on my bed. What a mess: jumping, leaping, butting heads, not to mention pooping. A couple had fallen off the bed, which would have been like falling off a giant cliff if they had been full size rhinos. But they were so light, the fall didn’t seem to phase them at all. This has got to stop. I’m in a sterile cancer ward for people with acute myeloid leukemia, after all. We can’t have tiny rhinos shitting all over the place. “Tihslub Tihslub make all the tiny rhinos and their by-products disappear instantly and no more coming out of the pillow.” With a puff of mist, all was restored.

What a relief. I still had one wish left since, as we all know magic wands and magic lanterns always offer three wishes. I stood up straight with a very solemn look on my face and spoke with a precise, articulated voice:

“Tihslub Tihslub, make my leukemia disappear forever!”

The wand started laughing. “No more wishes. You used them all up on tiny rhinos. Too bad.”

“What?” I proclaimed in dismay. “I thought I had three wishes. Isn’t that the rule?”

“Usually is,” the wand said, now without laughing. “But Loki decided to mess with you again and somehow managed to knock out one of the wishes. That’s Loki for you.”

Phooey. What else can I say at the end of this sad tale. But at least I got to see a few hundred tiny rhinos romping on my bed.

Love,

Uncle Rik

## Comments

Nice one, Erik :)

—Hillel Steiner, October 2, 2018

## Day 2, clinical trial

October 2, 2018

Today was the first day of major action: the dosimetric study to establish dose levels for the actual treatment. This entailed a six-hour infusion of the Iomab monoclonal antibodies, followed by imaging of my body to see where the radioactive antibodies have gone. That imaging will be reproduced several times over the coming week and on this basis a dose will be established for the October 12th full dosage when I am in the lead line isolation room.

The main drama of the day occurred early on. I woke up a bit out of sorts, a little queasy and tired. I was picked up by transport around 10:00 and half way down the many twists and turns in the corridors, I threw up over the side rail of the gurney. Man, did that feel good! It was a bit of a mess, but I felt much better afterwards.

As for the six-hour infusion, I slept deeply through most of it because one of the medications in the cocktail to deal with potential reactions to the radioactive antibodies included Benadryl. That completely knocked me out.

## Explanation for absence of postings

*October 6, 2018*

Two things have been going on : first, the Wi-Fi has been down in the hospital for three days and I hate typing on my phone. So I am dictating this to Marcia. And second, this has been one of the toughest patches I have been through and I will tell you more about that when I am able to write a proper post. I am doing much better today and things are still on track for the treatments beginning on the 12th which will lead up to the transplant on the 23rd.

## Comments

Oh no. Hope to see you tomorrow with Joel. You'll let us know if that's a bad idea, of course.  
xo

*—Sarah Siskind, October 6, 2018*

Thanks so much for posting news — thank you Marcia ... sending endless super strong vibes of support and prayers.

*—Isabelle F., October 6, 2018*

Sending you and Marcia so much love!!

*—Masoud Movahed, October 6, 2018*

Dear Erik (and Marcia) - know that you are in my thoughts everyday and that I am sending warmth and strength and positive energy and love. Even in the midst of this rough patch, may there be moments of clear sky, a glimpse of a flower, the crinkle of smiling eyes, and may those things give some measure of comfort, however small. Margaret

*—Margaret Vitullo, October 6, 2018*

Treatment and transplant--these two words are full of hope.

I know you are hanging on. By your fingernails, as they say.  
I also know you have the world's strongest fingernails.

I just wish there was some way I could grab you with mine and haul you back up to the top of the cliff.  
If only we could figure out a way to redefine or reconceptualize prayer.

Maybe we sort of have, here.  
I just wish it weren't called "post a comment"

Big digital air hug to you and M.

Nancy F.

*—Nancy Folbre, October 7, 2018*

Hi Erik,  
I'm so sorry that you've had some bad days. I'm assuming that we should not go see you tomorrow. If a visit works on Wed, Oct 10, then

*—Joan Fujimura, October 8, 2018*

Oops, the msg went off on its own. We can drive on Wed if that works for you. But I will be in Madison Oct 16 to 22 and can drive to see you during that time period. If that doesn't work, we'll plan for the future. My cell is 608-346-2818, if it's easier via phone. I wish you well, big hugs, take care, Joan & Kjell

*—Joan Fujimura, October 8, 2018*

## Much to write about

*October 9, 2018*



This is Tuesday afternoon, October 9 around 2pm. On Friday I begin the Iodine-131 treatments, which will put me in isolation for three to five days. I haven't posted anything in a while because I have been physically exhausted, really unable to write. But for the moment I have some energy, and much to write about. When I run out of steam, I will post as much as I have written and then continue when I can.

### **A gift from my students**

This morning two of my students, Peter Ramand and Kris Arsaellson, came for a visit and brought me the most extraordinary gift I could imagine: a digital scrap book of people taking selfies as they did the swabs for donations to the International Bone Marrow Donor Registry. I knew that some students had been encouraging others to sign up for the registry. I didn't know that there was a #Swab4Erik campaign and that more than 100 people had become donors as a result. The scrapbook is wonderful, filled with photos, some serious, some funny, but all brimming with love. Receiving this was emotionally overwhelming. I cried, tears streaming down my face. They sent me a link to a google docs where you can view the scrap book:

<https://drive.google.com/file/d/1Mg0O09HZH4QTc1pmTUVjv77L6W80e2oHN/view?usp=sharing>

This is a very big file on line, and it may be slow to load on your computer, but I think this should give you access to the scrapbook. I've also attached at the end of this posting a photo of the poster that Be The Match made for the #Swab4Erik campaign

## A week of difficulties

Last Tuesday, October 2, I had a sub-therapeutic dose of the Iomab monoclonal antibodies treatment I will receive in force on the 12th. That was a slow, five hour infusion in the Nuclear Medicine facility in the hospital. I slept through most of it. I had been coughing at night again and was tired. To deal with the cough I was using a combo of Robotussin without codeine (because of my aversion to codeine's constipation effects), Teslan Perls, and Benedryl. That brew had worked pretty well, but either it was becoming less effective or the cough worse, so my nights had become worse. The long infusion also had Benedryl administered IV to prevent some side effects, and the result was a lot of sleep. So I felt pretty well after that,

Tuesday night was pretty disrupted again, and then on Wednesday, out of the blue, my heart rate jumpy from 70 beats a minute to 160. That was full-bore atrial flutter. This was serious and had to be controlled. The cardio team was called in and they ordered various medications to try to bring my heart rate down. For the first time since April I was really scared. This could knock me off the clinical trial, which would seriously reduce my chance for a successful stem cell transplant. But also, 25 years ago I had a heart attack, and so the idea of a cardio complication was especially horrifying. The cardio team said that they had 48 hours to get this under control. By Friday my heart rate was down to 130, still far too high, still in atrial flutter. So they decided to take me down to the cardio procedures unit for an electric shock to the heart to try to reset the heart beat. This is like what you see on TV medical shows with paddles shocking a patient back to life from atrial fibrillation, only done in a more controlled setting. I was under general sedation and so didn't experience anything. It worked. My heart rate was reset in the 80s and has stayed there since.

Meanwhile, the stupid coughing continued. I relented and started the codeine. The coughing started. The constipating began. The pulmonary team was called in. The source of the coughs needed to be found before I went into isolation. No infections detected after many tests of different sorts. We need to do a bronchoscopy, declared the pulmonary team. By then it was Saturday. The only way to do so this was to admit me to the Medical ICU. I had been on the 7th floor of CFAC since September 4. I was going to be moved to the 8th floor for the October 12th procedure anyway. We'd been waiting for a room to open up. 6 p.m. procedure set in the MICU. So we're moved out of 7CFAC14 -- our stuff mostly going to our car -- and I'm moved to the UCU.

I only experienced the beginning of the procedure -- the rest was under full sedation: the doctor holds my tongue with a cloth and squirts lidocaine to the back of my throat. I swish it around to numb the back of my throat. Repeat five times. Then they give me what they called the happy gas and sent a tiny tube into my lungs to explore two areas identified by CT-Scan. Both areas showed inflammation, but no infection. The problem must be the fluid in my very distended abdomen that presses up against these inflamed areas causing the coughing.

Sunday moved to 8CFAC room 12. The procedure team for bedside ultrasound came to locate more precisely the fluid. It's not fluid said the head of the bedside ultrasound team. She tapped on my grossly distended belly like a tympanist. At the Madison Symphony we sit in the high box seats on the extreme stage right, hovering over the tympanist, who we all adore. She was definitely tuning me. Thump-thump, thump-hump. I joked, if the Milwaukee symphony needed a new tympany, I was available. The ultrasound confirmed: no fluid. Who puts water in a tympany after all? Next stop, Monday, more radiology to get a precise picture of where the air is. Transport takes me down to radiology. X-rays taken. Ah ha: it isn't air after all, but accumulated stool in the

upper colon, or something like that. That distends my guts, which I guess tympanizes my belly, and there is gas in the gut as well. But the problem isn't mainly gas or fluid in the belly. So we escalate the anti-constipation regime. Tuesday morning 4 a.m. or so the shift from constipation to diarrhea begins. By mid-morning that shift has been completed. Not bad. No desperate dashes with IV pole in hand to avoid a mess. But relief.

By Tuesday afternoon, all systems seem stable: heart rate in the 80s; temperature in the 97s; oxygen absorption above 95%; blood pressure 110/60; distended belly on the way down. Everything is back to a good equilibrium for the clinical trial. I am immensely relieved. I'm worn out, exhausted all the way down. I took a long nap in the middle of writing this -- I just couldn't keep my eyes open. Now it is 6 p.m. I have Carmina Burana blasting on my blue tooth speaker from my iPod classical playlist. Usually I just have classical music playing in the background; if it is too loud it distracts me from my thoughts as I write, but today I felt the need for something big, something powerful. It is a nice long piece -- a bit over an hour. And now, just as I finished writing about this week, I am near the end of the music. The ending is so full of beauty. About ten minutes from the end, a soaring soprano with the most ethereal melody then the full chorus coming in in full voice, and then the entire orchestra playing in full ensemble and the mighty tympany banging its heart out; and now back to the very quiet, staccato singing, repetitive haunting singing, one of the signature themes of the piece, with the woodwinds playing with chorus repetitive rhythm, repetitive motifs, the words in Latin, who cares what it means, and then wham: loud as any chorus could be and the orchestra in full-energy, still the repetitive motif, crashing towards the very end, in joyous ensemble ringing in every bit of power out of the music. And its done.

### **The story of the lost penis**

There is a wonderful story Marcia heard at a conference about two little children, maybe four years old, one a little girl and a little boy. The boy is peeing against a tree. The little girl says, "What a nice thing to bring on a picnic."

The ease of being able to pee without fuss is, I think, a male privilege that is pretty built into our sex-differentiated plumbing.

I'm 71-and-a-half. I suppose for about 69 years I've been good at this. It's pretty easy, after all: I stand up. Find a convenient place. Reach down and take hold of my penis which is always in the same place and pee. Great on long bike rides in the countryside.

Well, for the first time I can recall, this life-long simple way of relieving myself failed me. The scene: middle of the night, one of the nights of this past week of physical challenges coming from all directions. I've been coughing. Night sweats, so I'm sticky as well. I have been hooked up to heart telemetry to be sure my rate is stable, but this means more cables dangling from me. I wake up with a fairly urgent need to pee, one of the symptoms of the diabetes insipidus that has accompanied my leukemia. I stand up and grab the hand-held portable urinal conveniently by my beside. So far so good. Then I reach down with my other hand expecting to find the familiar apparatus for delivery of pee into the world. Where is it? A penis can sometimes behave like a shy sea creature that retreats into a hole in the sea bed when threatened. It is not always that nice flexible tube extending well beyond the body cavity. I fumble about, time running out. I grab what I can get ahold of and see if I can pull my reluctant sea creature from its hiding place. No luck, I pee all over the floor. And there was a lot of pee. Only at the end did I manage to get things right. To make things worse, because of the chemo, my pee is



considered a bit toxic, so the clean up needs to be thorough. I wasn't exactly embarrassed. It doesn't make sense to have any bodily embarrassment when you are this sick and need so much caregiving. But I was bewildered.

### **A painful, difficult moment of grief**

My mother died this summer on July 31 at one hundred and a half years of age. I was with her until an hour or so before she died, planning to come back after dinner. I had decided in April, when I was first diagnosed with leukemia, not to tell her that I had the disease. Initially, in fact, I planned to tell her, but when Marcia and I went to the assisted living facility in which she lived, the social worker said she thought that this would tremendously increase my mother's general level of anxiety. This could also, possibly, have lead her anxieties to get so out of control that her emotional state would completely unravel, so I didn't tell her. And, in any case, she would be happier not knowing.

This Saturday, Marcia's Dad, Bob Kahn, came for a visit with Marcia's younger sister Janet, Janet's wife Rosi, and Marcia's older sister, Judy. He has been living with us for several years and was now leaving for Burlington, Vermont, to live with Janet and Rosi, at least until we are able to be back in Madison in our normal situation. He is 100 and a half years old. We have good, connected conversations about life, death, the world, politics -- you name it. I have known him for 53 years; my own father died when I was 34. When I got sick, of course Bob knew all of the details, and this did indeed cause him real pain and sadness.

After he left from this visit, I had an acute awareness of the contrast between my relationship with my mother at the very end of her life and with Bob. I hid my suffering from my mother so she would not suffer; the depth of my connection to Bob has been enhanced because of my suffering, both because of words we have shared, but also just because of sharing the experience of navigating this difficult time.

Of course, the mental state of my mother and of Bob are completely different. Still, in April my mother would have understood the seriousness of my illness. Her cognitive abilities were sufficiently intact that she would have been able to talk to me about this. I ask myself: If I live to be 100 years old and one of my cherished daughters or grandchildren developed a life-threatening illness, would I want to know? Would I rather be "happier" by being spared the knowledge. Asking this question for myself now, the answer is unequivocal: I would want to know; I would want to share the suffering.

I don't think this necessarily means I made the wrong choice with respect to my mother, for the issue was not just how happy she would be, but also whether the information would simply make her life fall apart. She has relied on me for many years as the anchor for her own life. She lived in a good assisted living facility and received good care. They had to deal with her anxieties, and this did involve medication towards the end. So, her knowing that I had leukemia would have almost certainly meant that she would have had to be more heavily medicated because of the practical realities of the situation, and would therefore be less herself, less present in the world in her last months of life. That risk is what we avoided by not telling her. Probably this was the right thing to do; but I feel the loss of this struggle in my life not being part of hers.

## **Comments**



The gift from students is AMAZING. Wow. Really a remarkable expression of affection.

—Joshua Cohen, October 9, 2018

Was anyone ever so loved?

—Cathy Loeb, October 9, 2018

So much in this one post, Erik!

All those complex thoughts about your mom and Bob and who to share grief with ...

I think you did make the right decision about your mom, but I also really understand how you'd want to know!

And, yes, the students' surprise is amazing!

—Mary Jo Maynes, October 9, 2018

I feel so relived and energized after reading this post, dear Erik - especially given that the last week was very difficult for you. I will repeat what was said on the last slide: "we love you, and we can't wait to have you back with us soon!"

—Masoud Movahed, October 9, 2018

Thanks for writing--and writing and writing. I've read all your posts. They are amazing, inspiring.

Get well soon, Erik!

—David Schweickart, October 10, 2018

## Ready to launch

October 11, 2018

I have been pondering what would be the best metaphor for the period of isolation I will entering tomorrow. Two readily come to mind: (1) solitary confinement in prison, or (2) an astronaut launched on a solo mission. Yesterday felt more like I was headed for solitary confinement. I was in one of those listless, depleted patches. I dragged myself to exercise class at 1:30, and even though the exercises we do in the class are very mild, I felt they were all a major challenge. Half way through Marcia comes to tell me that the doctors want me to have an abdominal scan in order to more precisely see what is the source of the sharp discomfort on my left side and so I cannot eat or drink anything for six hours. I was already parched. I had been given IV Laisix, a pretty

strong diuretic, to help get rid of excess water. It had been working very efficiently, but normally it doesn't come with a prohibition on drinking anything. Or even sucking on ice chips. Is that any way to treat an astronaut the day before launch? No — definitely bound for a dungeon.

But no! It turned out that all they really wanted was a good abdominal scan. They got it, determined that I had a slightly enlarged spleen, which is one of the expected effects of leukemia. And then today they said, Hey, why not give Erik TWO units of red blood cells to ratchet up his hemoglobin even though technically he only needs one. Now that's the way you treat an astronaut the day before launch. So, definitely, tomorrow I will be an astronaut for five days or so starting when nuclear medicine begins the 4.2 hour infusion of Iomab iodine-131 armed antibodies eager to find their antigen targets on white cell and hematopoietic stem cell.

It is now 9 p.m. I am in the new isolation room, although not yet in isolation. Schubert piano is playing beautifully on my Bluetooth speaker. I am rested and, for the first time in over a week, really feeling at ease. Tonight I say goodbye to the bone marrow stem cells that have served me so well for 71 years, but it time for them to go and I will aid their exit with iodine-131. Then, after I am no longer a danger to others, some toxic chemicals will be added to the conditioning to clean out my bone marrow as much as possible, to get as close to a real myeloablation (wiping out of the bone marrow) as possible. This will be followed by a Total Body Irradiation to finish off the cleansing, and then, on the 23rd, my new stem cells will be infused. My rebirth day. Day zero.

Dear friends, dear family — you are all in my heart tonight. The love and connection that I have experienced from you these past months as we've moved to this moment have been immensely meaningful to me. I've described my image of my illness as a story, but tonight I really do feel it as a journey, and a journey I am taking with all of you.

## Comments

I'm so thrilled you're ready to launch eriki. Big transition and your attitude is nothing short of remarkable. Will be thinking of you every day and rooting for a full recovery. Lots of love!!!! Kathy

—Kathy Cole-Kelly, October 11, 2018

I'll be thinking about you, floating weightless above the isolation ward!

—Mary Jo Maynes, October 11, 2018

One big step for man, one giant step for humankind. Shoot the moon, Erik!

—Jeff Alexander, October 11, 2018

Vaya con dios! Safe journey and safe return

—Myra Ferree, October 11, 2018

We are with you as your launch. Feel all our love permeate and surround you. Love you ????????

—Lisa Baker, October 11, 2018

We are with you as your launch. Feel all our love permeate and surround you. Love you ????????

—Lisa Baker, October 11, 2018

Excellent astronaut ending, Eric! We are thinking of and with you all.

—Susan O, October 11, 2018

Rik,  
You know that the "Flushing Rosenthals" are thinking of you (along with your many other family members, and many, many friends and colleagues) . We understand this may be a rocky journey, but we are rooting for a soft landing.  
But I have a question? When I see you next, after the transplant and recovery, will you still be my first cousin, or first cousin once removed?  
May the force continue to be with you.  
Love,  
Wally

—Wallly Rosenthal, October 11, 2018

Hope it all goes well! Here's oliver, singing "What did I miss?", to keep your spirits up:  
[https://www.youtube.com/watch?v=E54M48RavJQ&index=25&list=PLM7yXcuYS\\_0aqPeHs\\_R\\_55ozTMghoGzlc](https://www.youtube.com/watch?v=E54M48RavJQ&index=25&list=PLM7yXcuYS_0aqPeHs_R_55ozTMghoGzlc)

—Harry Brighthouse, October 11, 2018

I will be communing with you from afar during this "retreat," Erik. Sending many hugs and much love...

—Cathy Loeb, October 11, 2018

We are with you Erik. Looking forward to your safe return.  
Much love.  
XXXXXXX

—Janeen Baxter, October 11, 2018

My heart and mind go with you as you embark on this journey - with you in every minute of it. So much love!

—Masoud Movahed, October 11, 2018

Sending love for the journey. Thank you for sharing. You have been on my mind all day - knowing what you must have been going through all day. You and Marcia will be in my heart all the way through Day Zero - your rebirth day. Jody

—Jody Whelden, October 11, 2018

John and I are thinking about you and caring about you and Marcia as you go into this.

—Pamela Oliver, October 11, 2018

To outer space! Talk when you are safely back.

—Stefan Svallfors, October 12, 2018

Eriki - I am holding you and your co-pilot/co-astronaut Marcia in my heart. You are both going to blast off today and for a couple who has traveled the world and many continents, I think this is your trip of a lifetime. Love you both, Jenn

—Jennifer Wilgocki, October 12, 2018

All good luck on the journey, Erik !

—elliott sober, October 12, 2018

Dear Erik,  
I am right behind you and Marcia in spirit.  
In loving affection for both of you

—Mansoor moaddel, October 12, 2018

Sending much love for a smooth trip, Eriki!! ??????

—Amelie Davidson, October 12, 2018

Dear Erik,  
Sending all love and support to you and Marcia at this important moment. You're amazing, as ever. Julia

—Julia Adams, October 12, 2018

Sending all the love on this new phase of the grand adventure! Happy launch!

—Josh Wright, October 12, 2018

## Launch day

October 12, 2018

8:30 a.m. I want to write about my experience in the upcoming period of isolation in real time, to bring you with me. This may not in the end be all that interesting. Mostly the isolation means I have to take care of everything myself, but, alas, I won't get some glorious view of our wonderful green and blue planet floating midst the stars out the window — just the helicopter landing pad for the hospital and Milwaukee trees beyond. But we'll see. Right now I have a pile of pills to take, a shot to the belly to self-administered and a cup of coffee to drink. The nuclear safety people will be here soon to wrap the remaining unwrapped items — cell phone, iPod, speakers, iPad, and the desk chair I have been provided for my work station.

My thought is to more or less accumulate these blogs into daily accounts, but I will send this one off right now since it is still pre-launch. I am defining liftoff as the beginning of the infusion of iodine-131 monoclonal antibodies, which will be later this morning. Stable orbit begins when the drip ends 4.2 hours later. I think this is a satellite expedition rather than a trip to the moon. Let's be realistic after all! My fond hope is that I now be like poor Laika, the Russian space dog who burned up on re-entry on November 3, 1957.

## Comments

All travelling with you. As far as you will go. Sending you endless sources of energy through these hours. You are going to teach us even more on your way forward. Thank you for your so generous sharing. Thank you. ?  
??????

—Isabelle F., October 12, 2018

Sending you infinite love from near and afar!

—Valeria Galetto, October 12, 2018

Good luck on your journey! Xo

—Heather Crowley, October 12, 2018

You are in heart and mind!! Sending you and Marcia so much love as you launch -

—Masoud Movahed, October 12, 2018

## Launched

October 12, 2018



10:30 a.m, Cnetral Daylight time, Milwaukee, Wisconsin, USA, Earth.

I am launched. I used to as a kid sometimes have my address include Earth, Solar System, Milky Way Galaxy, The Universe. It seemed fitting to do some of that now. I'm getting very sleepy because the pre-meds include a heavy dose of Benadryl. No need to fight it. So I'll to bed.

12:45.

Benadryl has worn off a bit. I decided it is best to be out of bed as much as possible, rather than treat lying down as my basic star of being and only up to do something. So I'm up. The main action this morning has been

taking my vitals every 15 minutes for the first hour, then every half hour. The Benadryl would knock me into real keep, the the nurse would call out, “Time for vitals.” I would rouse myself, do the blood pressure cuff first, the temp. Yell out the numbers. Then drift back to sleep. Music in the background. The last one was the Firebird Suite. Once again, I was transported by the ending. So beautiful, so meaningful for my “rebirth”. One of the nurses poked her head in the door and asked what it was. I told her, and replayed the last transcendent five minutes cranking up the speakers to the max conducting as I did a few weeks ago. This time when it was done and the audience applauded, I felt that the applause was for me.

1:45

I have been referring to the room as “lead lined.” That is a bit overblown. Basically wha the radiology safety people have done is create some shielding between het part of the room where I spend nearly all my time and the rest of the room. The picture below gives the main ideal — portable shielding panels. And the isolation is not to astronautish as I have imagined: nurses and radiology safety come in the room, wearing radiation-measuring badges. I just has a nice chat with the head of the radtiology team about the upcoming baseball playoffs and the prospects for the Brewers.

## Comments

Thanks for sharing the photo. Good to know that your isolation area is not as carcel-like as one might fear. For whatever it's worth, many of us are reaching across time and space to hold you, so in addition to the windows, it's kinda crowded in there!

—Margaret Vitullo, October 13, 2018

## Unthetherd

October 12, 2018

5:45 p.m., Friday, October 12.

I didn’t mean to actually post the last entry until later tonight when the day was done, but when I added the photo, I seem to have submitted the entire posting. No matter.

I am now in stable, low earth orbit. Coasting. The infusion ended an hour or so ago, and so I was able to be disconnected from the oxygen absorption monitor attached to a finger on my right hand. It is really a pain to type with one finger ensnared into a device, but now that is gone. And shortly after, I was untethered from my IV poles! Usually the PICC remains connected to the pole with a very slow saline drip “to keep the line open.” But for the period of isolation, it now seems they will carefully disconnect me except when I am actually

receiving medications. The Schubert *Trout* string quintet is playing on my iPod. An amazing recording done in 1969 of Jacqueline du Pre (cello), Itzak Perlman (violin), Pinchas Zukerman (viola), Zubin Mehta (Bass), and Daniel Barenboim (Piano). The performance is deeply poignant because we now know, of course, that soon — 1973 — Du Pre would be diagnosed with MS which would end her career. She would die at age 42. But in this performance she is young and vibrant, 24 years old at the height of her powers. And what an ensemble! All of the other of these young people — all about my age — have gone on for four decades making the world a better place through music. This particular recording is embedded in a documentary film about the performance, which adds charm. This may not be the best recording of Schubert's wonderful piece, but I love it. And here I am, nearly 40 years after it was performed, listening to it while writing to you and orbiting the earth.

6:45 pm.

Marcia dropped by to drop off some apples for me — I'm very particular about what constitutes a good apple. They need to be tart and snappy-crispy-juicy. She succeeded in two. She couldn't come into the room, but she waved from the corridor. Soon the nurse will bring some of my evening meds. I think I will now try to do a little FaceTime with Jenny.

9:30 pm.

The day is winding down. Last set of evening meds done. Marcia and I watched the final episode of *The Unforgotten* more or less synchronized: we were on FaceTime so we could smile at each other and watched it on different devices on Amazon Video. It really is a terrific series, one of the most interesting we've watched. Synchronized watching isn't the same as being together, but still nice. The Brewers game is on the ESPN audio app. They're ahead 5-1. Nice source of banter when I interact with various providers in the hospital.

So Day 1 of isolation has not proven to be demanding in any way. Indeed, I feel wonderfully at ease in both body and spirit. It is a strange moment. For six months our goal was getting to the transplant arm of the Iomab clinical trial. We are there now. Much has been made of the isolation phase, where I am a danger to others because of my radioactivity. Everyone is handling this situation with grace, and the isolation is not so total as to feel like being cut off from people.

## Comments

Erik, I loved thinking about that music with you. I grew up with the most beautiful music in the house, even though I never paid much attention (other than to get annoyed that my father was blasting Beethoven or Rachmaninoff or Schubert at 7 AM on a Saturday morning). Now hearing this music gives me so much comfort, but it also makes me weep. I am sitting on a pile of my dad's old CD's, in some cases 3 or 4 CDs of the same piece, played by different musicians. I am sure I have the one you are talking about; I will have to look. You are only in physical isolation, you see. Not emotional isolation. We are with you in there, listening to your musical mind.

Lots of love!

Rachel

—Rachel Schurman, October 13, 2018



Thinking of you!!

—Becca Krantz, October 13, 2018

## Day 2, earth orbit

October 13, 2018



8:00 a.m.

This illness is capricious. There have been times before when I have suddenly felt really well. Not just “not sick”, but really well, at ease in my body as I’ve said before. It like that today. I don’t expect this to last, of course. My white counts and neutrophils are plummeting. I am expected to have fevers, perhaps not from infections, but vaguely specified “neutropenic fevers.” That may be the future; so be it. Today is wonderul. I even took the bold step of ordering an omelet for breakfast. I probably won’t be able to eat it, but I thought it was worth a try. The protein-enhanced chocolate milk shakes remain my staple and they’re satisfying enough, but perhaps today my taste buds would be more at ease in the world.

The view from my window is the same as it was when I was on CFAC7 — overlooking a flat rooftop and the helopad across the way. On CFAC7, the roof was right outside the window, with all of the construction material assembled into my beautiful sculpture garden; here I am above it looking down (see photo below). In September, in one of the windows diagonally across from my room, was a window filled with fantastic LEGO constructions — London Bridge, ornate Victorian houses, carousels. Many had lights in them. They were lined up against the window, so when then shades were drawn it was easy to see them: at night, with their lights on; in the early morning illuminated by the sun. Marcia met the father of the young woman in the room, I think in her 20s, who was dying from bone cancer. The father told Marcia that there was nothing left that could be done. On one of our mile walks through the corridors on CFAC7, the door was open, so Marcia and I could peak in. There was a large gathering of what I am sure were family members. We were invited in briefly to admire the LEGO world surrounding the patient. The young woman was in bed, hooked up to two IV poles and oxygen. On a large table a young man, perhaps a brother, was busily working on a new LEGO building. The father showed us the latest construction set they had acquired: the Sydney opera house, something like 5000 pieces. The room was a glorious fantasyland of these buildings, an affirmation of life and passion.

This morning I looked down at the window where the LEGO buildings had rested. The window was empty. It's heartbreaking. I cried.

11:30 a.m.

I have been peacefully writing all morning on the letter to my grandchildren. I was given the usual pile of pills to consume and the self-administered shot in the belly, but these were placed on a tray and pushed down the counter for me to take care of whenever I wanted to. Aside from that, just me, my iPad, and Schubert quartets on my iPod.

I'm writing a section called a "Primer on Politics". As I think I mentioned in an earlier post, I had thought that this was something I would leave until later in the letter, after I had told the stories from childhood, but in talking about my grandparents in the 1950s, it was impossible to explain their lives and their impact on me without talking about the Cold War and communism, and I could do that without some sort of basic discussion of politics and social justice. So I decided to write a primer on progressive politics pitched at an intellectually engaged 12-year old. This is great fun to write. I'm trying to strip things down to the bare essentials, the simple core, and then add in a few complexities. I think it will be understandable to a 12 year old, but it may not be *interesting* for some. I hope Safire, Vernon and Ida will be interested in political ideas ten years from now, but in any case they will have this record of how I think about the issues.

noon.

Brief interruption from Earth: I needed to get attached to my IV pole to get platelets, since the morning blood draw indicated I had fallen below the critical threshold. I am also now completely neutropenic — almost no detectable white blood cells or neutrophils. But my hemoglobin remains delightfully high from yesterday's two units: 9.2! That is still way below the lower threshold of normal, but very high for me. No wonder I feel such solid energy level. I understand there are trade-offs of having lots of transfusions which make you feel better in the short run but increase various risks, but I will talk to the transplant team about this. This newer threshold is wonderful for now.

Marcia dropped by with her dear friend from California, Ellen Zucker. They are staying at the hotel across the street from the hospital while I am in this state of quasi-isolation. They couldn't come into the room, but we could open the door, exchange some sweet words, and wave.

## Photos





## Day 3, low earth orbit

*October 14, 2018*

8:30 a.m. October 14

The reason my posting for yesterday stopped in the afternoon was that I crashed — not my space capsule; I continue to be orbiting in isolation — but my physical state. I went abruptly from being wonderfully at ease in my body to being completely ill-at-ease and depleted. For the rest of the day I could barely manage the basic tasks I had to do — taking my vitals and pills, getting out of bed to use the rest room. It seems that the blissfully healthy feeling I had for the first part of the day was probably to a significant degree the result of the high dose steroids I had had during the launch of Iomab. When they wore off, I crashed. When I was told about the steroids I was very disappointed. I had thought of my energy and good feeling yesterday morning as reflecting my body's recuperative powers, my resilience, or even just the capriciousness of the illness. But it turns out to be the artificial result of steroids.

My night was also pretty miserable, and I felt the reality of my radioactive isolation. Previous nights when I have felt so poorly, Marcia was there to pat my head, rub my back. That physical contact made things so much



better. Last night I was completely alone. This morning I feel a little better, just enough better to write this, take my pills and give myself the Enoxaparin injection. Then back to bed. Maybe more sleep will revive me a little.

4:10 pm.

I've been in bed all day sleeping, dozing, drifting, and decided one way or another I should try to sit up, for a while anyway. I've mostly been listening to music. When I listen to an audiobook, which normally I enjoy immensely, I keep having to backtrack to find where I nodded off. My friend (and former teacher: he was my TA in a class I took from Talcott Parsons as an undergrad half a century ago) Mark Gould emailed me a number of musical suggestions, mostly obscure ones, at least in my repertoire. I first tried Messiaen's Quartet for the End of Time. I do my homework assignments, so I listened to it. I am sure I would love this piece in concert, and parts suited my current circumstances, but mostly it was too far off my usual palate. Then I listened to a piece he suggested by Arvo Part called "for Alina". That piece is extraordinary, and perfect for me right now. I don't think I've ever heard it before. Solo piano, very slow, no bombast, mostly single notes rather than chords, mostly played in the highest register of the piano with occasional dips to the lowest. Mark described it as melancholy, and it is, but it is also soothing, for me anyway. The music is filled with pauses and hesitations, some long silences. Somehow for me it says: drift now without expectations, the moment is hard, sad, but things will be alright, and sad is OK. I've listened to it now three times, one a ten-minute version, the other two a twenty-minute version. I don't know if one or the other is considered "definitive", but I like the longer version because it's longer. I found it on YouTube under "Arvo Part for Alina 1976" played by Hawkins Tanitasok. (I just got another email from Mark saying that the piece is meant to be played at different lengths, so neither of the two versions I listened to are the authoritative version. But I added the longer one to my classical playlist on YouTube.)

Now, also on Mark's suggestion, I'm listening to Coltrane's "Ballads." I've never really appreciated jazz. I like it as "background music", but generally don't connect to it with focused listening. But I thought I'd give this a try. My first date with Marcia in October of 1963 — 53 years ago! — was to a saxophone jazz concert — Stan Getz. I didn't especially like the concert, but I immediately knew Marcia was something special. So here I am, right now, in Froedtert Hospital, 8CFAC9, half a century later listening to saxophone by Coltrane. It is beautiful. And to think: I can be in my hospital room (aka space capsule) exchanging emails with an old friend, who makes a suggestion he thinks will be engaging for me in my current condition, and all I have to do is put the suggestion in the search bar on YouTube and then be transported to the sound of an ethereal saxophone from a wonderful recording made in 1963. All of this has made me feel better, in body, not just spirit.

8:00 pm.

My day is winding down. I've managed to get sitting up for four hours which, believe me, is an accomplishment. I watched the first hour of the film on Netflix, "July 22", about the neo-Nazi attack on the youth camp in Norway in 2011. I had heard a discussion on NPR and wanted to see how this was handled. The film is extraordinary, and I would also say important. There is about 30 minutes which about the shootings themselves, but mostly it is about the response of Norwegian society and the affirmation of its values. I recommend it on the basis of what I have watched so far.

But now it's time for me to call it a day. Marcia will be by soon to wave through the door. Then I have evening meds. And then to sleep.

## Comments

So moved by your descriptions of this strange and even surreal experience. John and I send caring thoughts from Ann Arbor.

By coincidence, I talked to a friend of mine who mentioned that her father-in-law had the same illness you have. He's 90, been living with it for ten years. Some exhausting times, and spells of being treated but it sounds like he's also been able to live normally, travel most of the time.

—Eve Silberman, October 14, 2018

Good night, Eriki. I am going to spend some time this week writing to you about some very powerful multiracial dialogues, co-witnessing, deep listening, and connection that I and others experienced this weekend at the event I helped organize. Love you and so grateful for your sharing of your life and current experience with me and other ???????. Sweetest dreams, uncle Eriki .

—Lisa Baker, October 14, 2018

I discovered "The Graceful Ghost Rag" this summer and found it ethereal and beautiful. Give it a listen when you want to drift and ebb and flow...

[https://www.youtube.com/watch?v=o-\\_Al\\_AX0JA](https://www.youtube.com/watch?v=o-_Al_AX0JA)

—Josh Wright, October 15, 2018

## Day 4, in orbit

October 15, 2018

10:45 a.m.

Today I'm feeling pretty good, and it's not because of steroids. No foreign substances capable of boosting my energy have entered by capsule. It's gotta just be because of my superhuman powers as a resilient spaceman! And I'm scheduled for a unit of. Blood later this morning, so I should be fully charged this afternoon. My agenda for today: Marcia can now come into the room for a half hour because of the drop in my radioactivity. SHE'll be here soon with her friend Ellen, so I can have a half hour with each of them. Isolation is eroding. Then I'll probably snooze for a while.

2:25 p.m.

Snooze I did. On and off for several hours after Marcia left. Floating in space. Delightful. But now i'll try to

stay awake for a while. Red blood cells are dripping in, which should help.

7:15pm

I thought I would be lively this afternoon and be able to work on my letter to grandkids. I did write for a little while after the transfusion of red blood cells was done, but then felt the need for a nap, and I slept the afternoon away. But it was happy napping—the sleep of the wistfully tired rather than of the wasted exhausted. Now I'm up for a bit, but it seems unlikely for an evening of fun and frolic. Marcia and Ellen will be by soon — they each have 15 minutes left on. Their 30 minute maximum exposure. And then, if I feel like I do now, I'll go back to my orbiting best.

8:45 pm

Marcia and Ellen just left and it's time for bed. A slow news day. Oh, I almost forgot, a little more information about my transplant on October 23rd. The bone marrow stem cells are being harvested not as stem cells from the donor's peripheral blood, but through bone marrow extractions. Because of the quantity of bone marrow needed, this requires general anesthesia and a two-hour surgical procedure. Most bone marrow stem cell donors only give stem cell from their peripheral blood, but the clinical trial required actual bone marrow. This requires a much much higher level of commitment from the donor. I feel so deeply, profoundly grateful. I have several times referred to human beings as star dust from the infernos of supernovas that gets organized in incredibly complex ways that we call "alive" and then somehow becomes conscious of the fact that it is alive and then conscious that it is conscious. So here we have two beings made of stardust, one of which is trying to keep the other alive. In this grand and amazing universe, what could be more beautiful: compassionate stardust bound together through universal love.

## Comments

Indeed, as you elegantly and powerfully said, "in this grand and amazing universe, what could be more beautiful: compassionate stardust bound together through universal love." Sending you and Marica big hugs and so much love!

—Masoud Movahed, October 15, 2018

## Day 5, orbiting in isolation

October 16, 2018

7:30. PM

I have slept nearly the entire day today, and right after this I will go back to bed. I've tried several times to

write something more than a quick response to an email, but it was really hard. I managed half a paragraph in the letter to my grandkids, but that was very tough to do. I'm not in any pain — no headaches, no nausea, nothing like that — but depleted beyond my capacity to willfully work through it. So tonight, dear friends, I won't try to say anything clever or deep. I just wanted to connect, which even this minimalist writing accomplishes.

Good night.

## Comments

Sending you all the energy I have with lots of love! And this piece by Yo Yo Ma and the Silk Road Ensemble: <https://www.youtube.com/watch?v=OqpYJS1kwOY>

—Masoud Movahed, October 16, 2018

Sleep well, with the Brewers up 2-1. Tomorrow you'll find out if it's 3-1 or 2-2.

Oh, and in a few weeks, with some energy returning, you'll be able to comment on another area of minor interest: the meaning of the November elections.

In orbit, and/or isolation, we're all rooting for you.

Wally

—Wally Rosenthal, October 16, 2018

Lovely of you to even try to connect in your depleted state. You're such an inspiration eriki. Hope you're sleeping well right now and free of those sweats as the AML is being exited out from your body. Sending love, Kathy. Hi Marcia!!!!

—Kathy Cole-Kelly, October 16, 2018

Thanks for connecting! Love you, Eriki?? Night-night ?

—Lisa Baker, October 16, 2018

Erik, I'm glad you're not in pain. I hope your energy level improves.

—elliott sober, October 17, 2018

## Back to Earth



*October 17, 2018*

My radiation fell below the critical level so my isolation ended this morning, thus also ending my astronaut metaphor. My return to earth, alas, also had a hard landing: I spiked a fever of 102.9F. That triggered the usual hyper-activity by the doctors and nurses: blood draws for blood cultures, increased monitoring, chest x-ray. I felt pretty miserable, but sometime in the late afternoon the fever broke, and now I'm better. I'm out of isolation which means Marcia can now sleep in the room with me. I now have a short break from treatments, and then on Friday I begin four days of chemo to continue the process of wiping out my immune system. The 23rd remains the big day, the day we've been working for since April, the day of the transplant, my rebirthday.

## Comments

Welcome back.

—Sarah Siskind, October 17, 2018

Your inspiration is eternal, dear Erik! Sending you and Marcia big hugs and much love!

—Masoud Movahed, October 17, 2018

Nice you can reunite with Marcia. Hope the fevers stay away and you get a good night's sleep. Xoxoxo

—Kathy Cole-Kelly, October 17, 2018

Erik: Say hello to Marcia for me.

—Mansoor moaddel, October 17, 2018

Hi Eriki! Sending so much love! I'm glad my mom got to see you yesterday! My thoughts are with you guys. Also, I want an Eriki primer on politics written for a smart 12 year old! I think that would be so helpful! ?

—Amelie Davidson, October 18, 2018

## Unexpected

*October 18, 2018*

Today was a day with no treatment -- done with the isolation and the Iomab radiation, and at rest before the Fludarabine chemo which starts tomorrow. I did feel better than yesterday, but like yesterday, whenever I sat up to write after a very short time I felt so tired and worn out that I went back to bed. So, I basically slept most of the day -- restful, cozy, comfortable naps. After every hour or so I would sit up and try to write, but to no avail. At the end of the afternoon, Marcia said we should try to go for a corridor walk. It took a huge act of brute will to get out of bed. I felt that there was no way that this would work; it felt too much like previous periods of depletion where I could power myself through the exhaustion. But we left the room to give it a try. I put on a mask (because I am neutropenic --zero neutrophils), and suddenly I felt fine, off to the races, striding down the hall at a reasonable pace, holding onto the IV pole with my other arm over Marcia's shoulder and Judy, Marcia's sister walking alongside us. We did eight laps -- a full mile. I know, of course, that sometimes when you're sluggish exercise can make you feel more energetic. But I've never had the experience of today: it took every bit of willpower to get out of bed and then, instantly, being fully energized for a walk, and not a walk at a snail's pace, a proper walk. That was unexpected.

A second unexpected: From the start my leukemia has been hitched to diabetes insipidus. Unless I take the desmopressin nasal spray every 10-12 hours, I begin to pee about every half hour and feel desperately thirsty all the time. The spray provides a dose of the hormone ADH which basically regulates sodium levels in the body. It is pretty clear to me and some of my doctors that my AML was the cause of the D.I. But exactly how acute myeloid leukemia would cause D.I. wasn't obvious. One of my doctor's expressed skepticism that the AML infiltrated the hypothalamus or pituitary gland and damaged the neurons between them. He felt it more likely that the AML in the blood somehow interfered with hormone, neutralizing its effectiveness. If this were the case, then after AML was cured, the DI should disappear. He did a case report search and found two cases where this happened with AML with my mutations. SO, here is the unexpected: I have now gone 22 hours since my last spray of desmopressin and still no symptoms. The radiation has gone a long way towards destroying my mutated leukemia producing stem cells. There are no detectable blasts in my peripheral blood. Maybe I am going to be done with diabetes insipidus once I am completely cured of acute myeloid leukemia and no longer have to contend with the EV1L mutation.

Five more days to go until my transplant.

## Comments

Go eriki go!!!!!! Xo

—Kathy Cole-Kelly, October 18, 2018

You got this, dear Erik! Much love -

—Masoud Movahed, October 18, 2018

Eriki - I am doing the countdown with you. My love and support is with you and Marcia and the whole Kahn/Wright clan every day. Love Jenn

—Jennifer Wilgocki, October 19, 2018

## "No one expects the Spanish Inquisition"

October 20, 2018

### I. No one expects the Spanish Inquisition

There is a famous Monty Python skit in which two people are having a discussion in which one keeps saying she doesn't understand the other and keeps asking for clarification. Eventually, in exasperation, the first person says "I didn't expect some kind of Spanish Inquisition" at which point three medieval priests in inquisitorial garb burst into the room and proclaim "On one expects the Spanish Inquisition!". Here's a link to the sketch: <https://www.youtube.com/watch?v=7WJXHY2OXGE>. In our family this has become a kind of one-liner for something unexpected. Yesterday was definitely a no-one-expects-the-Spanish-Inquisition-Day:

I woke up refreshed, filled with energy. Went to my work station and wrote a bit on the letter to my Grandchildren. Answered some email. Drank a protein-fortified ensure chocolate milkshake (still my basic source of nutrition). Then around 9 a.m. a CNA comes in and cheerfully announces that it is time for my orthostatic vitals, a daily routine where I lie in bed and get my vitals taken -- blood pressure, temp, pulse and oxygenation. Then I stand up and get the same measurements. Then wait a few minutes and get them repeated. Lying down: All normal. I stand up, and Torquemada bursts into the room and announces in a caricature of a Spanish accent, "No one expects the Spanish Inquisition": My heart rate is at 150 and in atrial flutter. My blood pressure is low. I'm light headed. I sit down. Measurements retaken: the same. And thus begins a day of fixing me.

The cardiology team arrives and explains that they will adjust my medications in the hope of bringing down my heart rate. I get hooked up to telemetry for constant monitoring. There are two issues: the flutter and the rate. They're more concerned about the rate than the flutter. The plan is to get the rate under 100 and then hope that the rhythm converts to an ordinary sinus rhythm. They do not want to do another electrical intervention like they did previously, especially this close to the transplant, since it would be very unlikely to produce a stable fix of the problem. But they express confidence that everything will be brought under control quickly. I'm worried that this recurrence of the electrical problem signals some underlying heart problem, so I ask the cardiologist what was the cause of the heart beat instability. His reply: "Everything." He told me that it was very unlikely there was any underlying heart condition at work here. The problem is the interactions among all of the things happening in my body -- the radiation, chemo, other meds, the underlying disease. Everything. Sounds convincing to me. I then sleep most of the rest of the morning. Heart rate comes down, but the rhythm remains in flutter, occasionally flipping to fibrillation (meaning basically a chaotic rhythm). But no regular sinus rhythm.

I feel good in the afternoon and move to my workstation. Mid-afternoon I call my sister-in-law Janet to ask for meditation instruction on heart rate reduction. She does a wonderful guided meditation via phone: I have ear

phones, sitting in my desk chair, relaxed, rebalancing. Marcia looks at the heart rate on the telemetry and it seems that in the period of the meditation it might have been lower.

I go to bed very early -- in the second inning of the Brewer's playoff game (they won 7-2, but I didn't learn that until the next morning). In the middle of the night when I am briefly awake while being hooked to platelets the nurse tells me I am now in regular sinus rhythm. And now, 10 a.m. in the morning, 24-hours after the incident began, the sinus rhythm holds steady at 90 beats minute.

## II. Vulnerability and Fortitude

We have now been here in CFAC for 7 weeks. Marcia commented this morning that there moments when she feels a bit stir crazy. I said that there wasn't a single time when I felt that. I feel so deeply vulnerable and often fragile that being in CFAC mostly makes me feel safe and protected. This, of course, is not because of simply being in any hospital with technically competent nurses and doctors; it is because of the way this particular ward is organized: three patients per nurse, with each nurse working seven 10-hour shifts then having a week off, so they really get to know their patients and, equally important, the patients really get to know the nurses. As I think I noted in a very early posting, I feel I am a known-person here, not just person-in-a-role. The ward is quiet (except for some weekday construction noise) and night-time interruptions minimized and designed to give patients long blocks of time to sleep. The rooms are large and Marcia's bed comfortable. Her continual presence has mattered tremendously, but that was only possible because of the social and physical organization of CFAC. All of this contributes to my well-being, to my sense that there are things I don't have to worry about and that any Spanish-inquisition moments will be taken care of. So I feel safe.

Many people have remarked on my fortitude, resilience, optimism. It is true that I am lucky in having such dispositions. But I doubt if I could have sustained them in anywhere near as robust a way without the kind of protective social environment in which I have been living. My weeks here -- twelve altogether including the initial spring stay -- bring home in a powerful way such a basic sociological idea: individual capacities flourish or flounder depending on the social environment in which they exist. My capacity for resilient optimism flourishes here rather getting beaten down by worries and impersonal treatment. So, the outsider observes what I say and what I write, and attributes this all to my internal dispositions; the reality is that those dispositions are real, but they would not be sufficient for those words without these wonderful conditions.

## III. My donor

We don't know much about my donor. The rules are that it is only after a year that the donor is asked whether she would like contact with the recipient. The only official information given out is sex and age: a 29 year old woman. The head of the transplant team, Dr. Hari, asked me if I had signed a Mad Cow disease form? No, I said. Then, he proclaimed, your donor is from North America. If the donor had been from Europe I would have signed a consent form saying I understood the risk that I might get Mad Cow disease from the transplant. Since I didn't sign the form, my donor must be from North America.

## IV. The task ahead: fending off the rabbits

Yesterday, Dr. Hari, the head of my transplant team, dropped by to see how I was doing and say a little about what lies ahead. I said my daughters were coming in for the transplant and that I was planning a little ritual. "You know," he said, "the actual transplant is no big deal. Its just a bag of cells that get hung on your IV pole like all the transfusions you've already had. It's like planting a seed: pushing it into the ground. The real work

comes after that -- what you have to do to be sure the seed grows into a tree. There's fungus, rabbits, mildew. That's where the work is." OK: I get it. If you a specialist in stem cell transplants, the most challenging active interventions begin after the transplant. But if you are a patient who is told when diagnosed, the only way you can survive is with a donor transplant of bone marrow stem cells, then the key moment, the moment that confirms the possibility of a personal future, the moment when you receive the new hematopoietic stem cells.

## Comments

Hi, Erik, I've been reading all your posts, but rarely commenting. I care about you. I was also think about Marcia and how hard this is on her, too. I hope Marcia has people who can support her as she supports you. There are all the ideas of concentric circles of support, you support in and get support out. My love and prayers to both of you.  
Pam

*—Pamela Oliver, October 20, 2018*

This post is do filled with interesting insights. They nearly all are, but this one even more than usual! Have to discuss these thoughts more at some point but couldn't resist mentioning one small coincidence. This is the week in my course on the family from 10,000 BCE to the present where we discuss the Spanish Inquisition. Needless to say, I was surprised when it came up in your post.

*—Mary Jo Maynes, October 20, 2018*

I've been following your story and appreciating how much your sociology has been informing your perspective, and this is very pronounced in this account. I am not sure I could maintain the intellectual distance you combine so skillfully with evocative imagery of all sorts. My gardening experience has been shaped by rabbits -- so I am hoping and praying you are in a rabbit-free zone. You certainly have some very experienced and committed gardeners at work ! Wishing you a smooth "spring" as the seeds grow and the garden flourishes.

*—Myra Ferree, October 20, 2018*

I, too, am continually awed by your and Marcia's strength and the insights you share with a large 'public'. I presume there is a book here someday.

A side note on the feeling of safety. Several years ago, Tom discovered that he had higher than normal blood pressure. It turned out that he had not been diagnosed earlier because most people are nervous in the doctor's office and the medical community assumes that blood pressure measured in the office is elevated due to anxiety. Tom, on the other hand, relaxes when he is in care... so his blood pressure drops. The 'real' blood pressure was thus underestimated by the medical team. Of course, the office visit in his case is truly causal -- just like meditation. The issue is whether those recording and responding to the data interpret them well. Given the intensity of your care, and your own attention and analysis, the match between data, inference and action should be very high, and that seems like a good thing.

—Elizabeth Thomson, October 20, 2018

Erik,  
I am thinking back on the many conversations that we had while we were working on our "Gender Equality" Verso book. It is partly because of those discussions -- I remember your joy as we pushed some ideas as far as they could go (your own chapter!) -- that learning that your donor is a woman brought a quick smile to my face. It just feels so right.  
Love to you and Marcia and your extended family (and to your donor as well).  
Janet

—Janet Gornick, October 20, 2018

May there never be anymore of these unexpected moments that only cause more stress. I am so delighted that this was fully taken care of. You have got this, dear Erik! Your fortitude, resilience, optimism --and, of course, your inspiration-- are enduring and eternal!

Please give my best to Marcia - she is one of the kindest souls I have ever met in my life! Sending you and Marcia big hugs and much love!

—Masoud Movahed, October 20, 2018

When the "i" is removed, the result is hemato-poetic. You are.  
Hugs and peace,  
Margaret

—Margaret Vitullo, October 22, 2018

**Excerpt from the letter to my Grandchildren: a primer on**

## politics

October 22, 2018

As I've mentioned, I have been writing a "political primer" as part of the letter to my Grandchildren. A number of people have said that they would love to read it, so I decided that today would be a good day to insert it in the blog. I've also included a couple of paragraphs from the letter that immediately precede the primer where I talk about my grandparents. It was when I wrote this that I realized that I would need to explain something about politics in order for them to understand what I was writing.

### **An excerpt from the letter to my Grandchildren**

My grandparents on my mother's side of the family – your great great grandparents -- were Russian Jewish immigrants who arrived in the US in the great wave of Eastern European immigration in the early 20th century. They were both politically very left-wing and strong supporters of the Soviet Union. They were certainly socialists, and I think closely connected to the Communist Party. They would go to Kansas City sometimes for meetings of The Literary Guild, which I imagine was what is called a "front" organization of the Communist Party. You probably don't know the history of this period, the era of the Cold War between the USA and the Soviet Union. This is a complicated subject.

What I want to do now is give you a very brief lesson about politics, and then tell you how this played out in the 1950s. Yes: I am going to give you a LESSON. Remember, I'm a professor and this is part of what professors do – give lessons to students. And it turns out that this topic is one that is really at the heart of what I study as sociologist. Remember the line from the song to my grandkids that I sing to you: "Your Grandpa's name is Eriki, he likes to study sociology, and when he comes he talks to you about politics and cosmology." The cosmology bit came right at the start of this letter when we talked about the origins of the universe and stardust. Now it's time for politics. I thought I would leave this for a separate section much later, but then when I started writing about my grandparents in Lawrence, I realized I couldn't really tell you what they were like and how they mattered in my life without explaining something about politics. So, we'll just take a pause from the stories about my life in Lawrence and talk about politics.

### ***A Simple Primer on Progressive Politics for Safira, Vernon and Ida***

For starters, let's think about what politics is all about.

Consider the city in which you live. There are all sorts of things that can make a city a good place for people to live in: nice parks, good schools, safe neighborhoods, affordable decent housing, and many other things you might not even think of, like good sewers and safe drinking water. The city government (and other levels of government too, like the state and Federal Government) is responsible for providing a lot of these things. To accomplish this, the city government raises taxes and then decides how to use the taxes to provide for the many things government does in a city.

Here's the problem: Cities also contain rich people and poor people and people in between. In some times and places the difference between rich and poor is huge: the rich live in fabulous mansions or glorious apartments; the poor live in terrible, run-down crowded buildings in unsafe neighborhoods. In other times and places, the gap between rich and poor is not so great. Even people without much money live in decent housing, because it



is provided or partially paid for by the government. (I can't resist -- Here's a bit sociological terminology: These categories -- the rich, the poor -- are called "classes." This is one of the main things I've studied as a sociologist. The general way sociologists talk about issues like the size of the gap between the wealthy and the poor is the *degree of economic inequality*.)

Now, suppose you live in a city with a high level of economic inequality. You observe that in the rich neighborhoods, there are good schools, with beautiful auditoriums, well-equipped science labs, nice playgrounds and well-maintained sports fields. In the poor neighborhoods, the schools are falling apart, the roofs leak, there are no science labs, the sports fields are a mess. In the rich neighborhoods all of the streets are smooth, well maintained; in the poor neighborhoods the streets are filled with potholes. You feel that this isn't fair, and along with other people who share your views you want to change things. So you try to affect how the city spends its money by protesting, by talking to politicians, by voting in elections, by working on political campaigns, by running for office. You are engaging in politics!

What you discover is that to improve significantly all of these things would require a massive increase in taxes. Since the poor don't have much money, they don't pay much in taxes (although, actually, the tax burden on the poor can sometimes be pretty heavy). This means that to increase taxes significantly, you have to increase the taxes on those who have enough income to pay more taxes, and this means especially increasing taxes on the rich. But the rich already have nice public schools, good streets, beautiful parks. They also have private country clubs with great swimming pools and fantastic private schools for their kids if they want something even fancier than a good public school. Mostly, the rich therefore oppose high levels of taxation.

So what, you might think? The rich are a fairly small part of the city's population. There are many more people who would benefit from higher taxes, better services and other changes in the rules that govern a city. The city should do what benefits most people and raise taxes and provide these services. The problem here is that the rich may be small in number, but they are also powerful. They fund politicians' election campaigns. And they can threaten to move to the suburbs to avoid the higher taxes.

That's not fair! You get frustrated. It's terrible that a child born in a poor family has to go to a badly funded school, live in an unsafe neighborhood in a crummy run-down apartment. And then the rich use their power to block solutions. What a messed-up system. The people who benefit the most from the *status quo* -- that's a fancy word for "the ways things are" -- are also the most powerful and use their power to protect their advantages and prevent improvements for those at the bottom.

I've only talked about these problems for a city, but of course a city is part of a larger political system of state and national government, and all of these levels of government are part of social and economic system as well. (If you take all of this together -- the political, social and economic system -- you have more or less what we sociologists call "society.") So, when you think about politics you have to think about all of these levels of government and the broader society of which government is a part. Sometimes politics is intensely local, things like battles over schools, but other times politics become national, like battles over the role of government in a national healthcare system.

Some people come to the conclusion when confronting this reality that what really needs changing is this deep division of society into rich and poor. It is not enough to just try to have good policies -- although that is important; we must attack the conditions that generate such inequality, that generate rich and poor. Above all, the power of the wealthy has to be dramatically reduced and the only way to do this is for the wealth of the wealthy to be drastically reduced. This is radical politics, politics directed at changing the society as a whole.

So, Safira, Vernon and Ida, my dear Grandchildren, this is what politics is all about: trying to affect the way power is used in a society for various purposes. To state matters in the simplest possible way (of course things



are much more complicated) on the one side you have people defending existing inequalities of power and privilege; on the other side you have people concerned with what is called “social justice”, how to make the world a good place for everyone to live in. The names for the different sides of this divide change over history and can get quite confusing. One way people label the contrast is “right-wing” versus “left-wing”: the right-wing defends inequality in various forms; the left-wing opposes inequality. (The historical reason for the terms Left and Right is pretty weird: during the French Revolution in the early 1790s the more radical forces wanting to drastically change the society sat on the left side of the chamber; the delegates to the assembly who were opposed to such radical proposals sat on the Right side.) Other terms are conservatives versus progressives. In the United States the term “liberal” is often used to describe the Left, but in other parts of the world the term “liberal” gets used to describe people who want minimal government interference and are more like what Americans call conservatives. If this sounds confusing it is because it is confusing.

I’ve mostly been talking about Progressives versus Conservatives in terms of their political positions on matters of inequality and social justice. There is another, immensely important issue on which the Left and Right diverge: militarism and war. While it does sometimes happen that left-wing forces support military action – as in World War II when the Left generally supported the war against the Nazis and the Japanese – mostly the Left is associated with opposition to war, while the right-wing – at least in powerful countries like the United States -- is associated with aggressive international postures and militarism. It is possible, however, to be progressive on domestic social justice issues and nevertheless be rather militaristic when it comes to foreign policy. This has been one of the hallmarks of American politics since the end of World War II: The Democratic Party has combined progressive policies on at least some important social justice issues, but at the same time supported military interventions abroad.

Within each camp in this great political divide there are also often very big disagreements. On the Left there are disagreements over how much of a society needs to be changed in order to fulfill the ideals of social justice. Sometimes this is a disagreement just over what is practical: what can we actually achieve at this moment in history. But there can also be very deep divisions over what kinds of social changes would actually accomplish the goals. Do we simply need to increase taxes on the rich in order to fund programs to make life better for the poor and everyone else, or do we really need to destroy the system that generates such inequality in wealth in the first place? And to make things even more complicated, a person can believe both (a) that to really solve the injustices of the world we would need to destroy the system that generates these inequalities in the first place, not just increase taxes with good government programs, and also (b) that it is impossible actually to achieve this because of the power of the wealthy, and so the best we can do is try to make small improvements through taxes and good government programs. On the left, people who believe that the whole system should be transformed from top to bottom are called revolutionaries; people who believe that the best we can do is make incremental changes to improve things are called reformists. And some reformists — like me! — hold to revolutionary ideals, but feel that the only practical way forward is through reforms, often quite modest reforms. (Someday you might want to read some of the books I have written about this. At the time I am writing this — it is now October 2018 — there are two books I’ve written that I am very proud of that try to address these problems: *Envisioning Real Utopias* and *How to be an Anti-Capitalist in the Twentieth Century*).

So that is the left-side of the political spectrum: revolutionaries and reformists, and among reformists varying beliefs about how profoundly the society can be changed through gradual reform. On the right-wing side there are also deep divisions. There is what is sometimes called the “moderate” right-wing that believes in some government programs to help the poor and also feels that the government should have responsibility for funding certain things of general public value like education. The moderate right-wing also generally supports values

like free speech and democratic elections. The “extreme Right ” often doesn’t care about democracy and is happy with a dictatorship that represses popular social movements. Again things can get really complicated: the extreme Right sometimes defends what it is doing in the name of democracy and freedom, even when it supports very anti-democratic policies. And generally, in the 21st century, when conservative political forces denounce high taxes and government programs they do so by saying that these policies actually hurt the poor. Give more money to the rich by cutting taxes, conservatives say, and they will invest that money, create jobs, and thereby help the poor. Some people really believe this, but for many people this just a way of justifying, their privileges and advantages. I think such views are fundamentally flawed and become a political smokescreen for selfishness and greed.

You might think that along with these political stances, there would necessarily be big differences in the personal character of people who support the Left and the Right: people on the Left should be kind and generous; people on the Right, mean and selfish. It doesn’t work like that. There are plenty of Conservatives who are kind-hearted and loving people, who in an emergency in their community will pitch in to rescue people, and who give generously to worthwhile charities. And there are plenty of people on the Left who, in their personal lives, can be aggressive, selfish, mean.

There is one final kind of nasty complexity to this story about politics. So far, I have been talking mainly about issues concerning *class* — rich and poor, social justice in how the wealth of a society is distributed and how people get access to the resources they need to live good lives. But there is a whole additional dimension of politics which concerns social issues like race, sexuality, religion. There are “social” conservatives who might not be so opposed to programs to help the poor, but are strongly opposed to same-sex marriage and want to impose their beliefs on everyone else. And, of course, in the United States there is the especially damaging politics of race (or similar categories like ethnicity or immigration). Conservative forces often form coalitions that combine social conservatives, racist conservatives, and the kind of economic conservatives I have been mainly talking about.

OK, enough of these general matters and all of this complexity. The bottom line is this: throughout much of modern history the biggest political cleavage has been between Left and Right, progressives and conservatives. In the 20th century this cleavage got an added, powerful twist: The Russian Revolution, Communism, and the Cold War. Here is the basic story in a nutshell.

In 1917 there was a Revolution in Russia lead by the Bolshevik Party and a political figure named Vladimir Lenin. Before the revolution, Russia was a backward country ruled by a Czar in a ruthlessly authoritarian way. The masses of the people were desperately poor, mostly illiterate peasants in the countryside; the elite was fabulously wealthy. The Russian Revolution became possible because the Russian Czarist Army collapsed in 1917 because of WWI. What followed was a horrible, difficult series of violent conflicts, including an intense civil war in Russian between the Red Army (the Left, communists) and the White Army (anti-Bolsheviks supported by the United States and Europe). In the end, the Communists won, but at a terrible cost. They established a new country, called the Soviet Union (short for the Union of Soviet Socialist Republics, or USSR). This new country was committed to an entirely different way of running the economy. Instead of rich people running the economy in their interests based on their private ownership of land and businesses ( an economic system that is called “capitalism”), the economy would be run by the Government on behalf of the entire population. That new system is called Socialism. The key idea was that the government could plan the economy in a way that would benefit everyone, eventually insuring that everyone would have access to the resources to live good and decent lives. These were the ideals of the Left taken to an extreme.

The ruling elites in United States and Europe were really freaked out by the Russian Revolution. They initially did everything they could to overthrow it, and when that failed, to isolate it. The conflict between the political Left and the political Right, between progressives and conservatives, suddenly had also become a conflict between countries.

The story now develops both within the Soviet Union and within Western countries like the U.S. In the West, Communist Parties were established which were dedicated both to defending the Soviet Union and to participating energetically in struggles for social justice within their own countries. In the U.S. the communists were very active in struggles for workers' rights and for civil rights for African Americans. But they also supported the Soviet Union, often completely uncritically and often in ways that opposed the international policies of the US government. Communists were therefore accused of being unpatriotic and un-American, of being "agents" of a foreign government. The truth of the matter is that most Communists deeply believed that social justice would be best served by socialism. They wanted an America that would embody those ideals and engaged in struggles for that purpose. They also believed that the Soviet Union was the leading force in the world that supported these ideals and that it was a very high priority to defend the Soviet Union against all attacks.

In the USSR it turned out that it was much much harder to "plan" an entire economy than the revolutionaries had thought, and economic conditions got quite bad. There were conflicts within the Soviet Communist Party over what to do. Lenin died in the early 1920s. By the late 1920s a new leader emerged, Josef Stalin. He ruthlessly implemented five-year plans, and violently crushed any opposition to his policies. By the mid-1930s the system in the USSR came to be known as Stalinism: a combination of highly centralized planning of the economy from above with highly repressive, dictatorial political institutions in which anyone who opposed Stalin was imprisoned and many executed. Any remnants of democracy and individual liberty had disappeared.

In the West this period also saw democracy in decline. In Italy the Fascist Party, led by Mussolini, took over and replaced democracy with brutal right-wing dictatorship in the early 1920s. In Germany the Nazi Party, led by Hitler did the same in 1933. In Spain there was a terrible civil war – the Spanish Civil War – that started in 1936 when a General, Francisco Franco, lead an army rebellion to overthrow the Democratic Spanish Republic. The Nazis came to his aid, and by 1939 he had won. Another brutal right-wing dictatorship in Europe. His dictatorship lasted until his death in 1975. In the United States, in contrast, politics took a Left turn in the 1930s with the election of Franklin Roosevelt and initiation of a set of policies called the New Deal. The New Deal was definitely progressive and reformist, and it contained elements that could be called socialist, but as a whole it designed to revitalize American capitalism rather than be a stepping stone to more radical transformations.

All of these developments made the political landscape way more complicated. Traditionally the Left in politics was strongly associated with the idea of democracy, not just equality and social justice. Conservatives had only a weak commitment to democracy, fearing "mob rule" and the "tyranny of the Majority", so it wasn't surprising the right-wing forces, in conditions of instability, often chose dictatorships. But the Left always supported the idea that ordinary people should have the power to rule, to govern, and that is the basic principle of democracy. Stalinism made a mess of that idea. I think in general Communists in the US and Europe were strongly in favor of democracy, but they also wanted to defend the Soviet Union against attacks. So, mostly, they simply denied the facts of the matter, claiming that that Soviet Union was a new kind of democracy – a People's Democracy that was more profoundly democratic than what they called "bourgeois democracy" – and describing every report of mass executions, large prison camps, repression of artistic expression, and other acts of dictatorial rule as Western anti-communist propaganda.

Things got even more scrambled up during WWII: The Soviet Union at the outset of the war actually became

an ally of Hitler. The Nazis were extremely anti-communist, so for most of the 1930s communist Parties all over the world were extremely anti-Nazi. Then in 1939 the USSR signed a non-aggression pact with Hitler in which the Germans pledged not to attack the USSR and the USSR pledged not to attack Germany even if Germany waged war with countries bordering the USSR. Immediately after this pact was signed, Germany began World War II by invading Poland.

This made for a very messy political situation in the United States and elsewhere for Communist Parties, who suddenly opposed any military aid to the countries fighting Hitler. Then in June, 1941, Germany suddenly invaded the USSR, so of course Communist Parties changed their position. All of this led many people to believe that the Communist Parties were really political tools of the Soviet Union rather than autonomous political parties committed to principles of social justice elsewhere.

The United States entered World War II six months later and suddenly found itself an ally of the Soviet Union against the Nazis. The U.S. Government, during the New Deal, was broadly supported by Progressives, and some prominent figures within the government were themselves strongly associated with the Left.

After the war, the political configuration changed dramatically. The Nazis in Germany had been defeated as had the Fascists in Italy. The United States was working hard to rebuild Western Europe. The Soviet Army occupied Eastern Europe and, basically, installed Communist Governments there. In China, after the defeat of the Japanese, another Revolutionary Civil War was taking place, the Communist forces being led by Mao Tse-tung, against the anti-Communists. In 1949 the Communists won. Suddenly it seemed that Communism was on the march. Roughly a third of the world's population was governed by Communist Parties. And in at least some non-Communist countries, progressive parties were also gaining power – in Scandinavia and in Britain most notably. In these countries a range of very left-wing policies were enacted with strong socialist components, like National Health Services and nationalized railways. All of this created a sense of tremendous uncertainty about the future.

This is the context for what came to be known as the Cold War between “the West” and “the Communists”, which lasted from the late 1940s until the late 1980s. The Ruling Elites in the United States and Western Europe hated Communism, for even if it did not live up to its ideals, especially because of the undemocratic character of Communist regimes, communism did show the world that another system was possible. This was especially salient for less developed parts of the world: would they follow the course of capitalist economies, enter the global market and provide resources for Western corporations, or would they attempt a communist road to the future? It simply wasn't clear what the future held.

One thing was, however, very clear: that anti-Communism could be used as a weapon against the Left more broadly. Reformist socialists were always wary of Communist Parties because of their apparently weak commitment to democracy and their uncritical praise of the Soviet Union, and sometimes socialists became quite anti-communist as a result. But they were nothing like the right-wing, who took anti-communism to an extreme and used it to attack the entire left. This succeeded to different degrees in different countries. In United States, Conservative forces managed to define the threat from Communism as including anyone who held even reformist socialist views. The USSR was portrayed as bent on World Domination, and communist ideology was seen as a kind of virus that spread and infected people. Communists and “fellow travelers” were purged from labor unions, Universities and many other organizations. The suppression extended far beyond actual members of the Communist Party, but included sympathizers and others who held anti-capitalist ideas.

This active, vicious repression of Communists was especially intense in the 1950s. Congress held hearings about so-called un-American Activities. Most notoriously, a senator from Wisconsin, Joseph McCarthy, held hearings about the presence of Communists in the Government and in Hollywood. People were forced to testify

before committees of congress and asked “Are you now or have you ever been a member of the Communist Party?” They were asked to “name names.” If they refused to answer questions they could be charged with contempt of Congress and face possible imprisonment. This created great fear and intimidation.

Well, to end this *Primer on Politics* let’s jump to the present, 2018. I will tell you more about politics when I write about my years in high school and college and the Vietnam War, and then my work as a professor. But for now, let me say this: The basic cleavage between the Left, which wants to create a more just and humane world, and the Right, which wants to preserve privileges and inequalities, remains a central axis of politics. New issues have emerged – the environment, climate change, multiculturalism, sexual identity, immigration -- but mostly these still break down into a progressive, left-wing versus a conservative, right-wing position.

There no longer exists (at least in 2018 as I am writing) a significant, politically-potent revolutionary, extreme Left in any developed capitalist country, but there are certainly many people on the Left who continue to share the values and ideals of democratic socialism. And there exist many vibrant social movements, movements organized by ordinary people struggling for social justice and a more humane world that firmly hold to the value of the Left.

There continues to exist, however, an extreme Right , which holds the same antidemocratic views of earlier generations and which seems to appeal to a significant minority of the population in the United States and elsewhere in 2018. This is a matter of tremendous worry because it poses a fundamental threat to our democratic.

There also exists a “Center”, which tilts to the Right or the Left at different times and places. The Center sometimes can play an important role in being a political force for needed compromises. But. at least in 2018, the Center does not seem to stand on firm ground with solid vision for the future.

## Comments

Especially sending good vibes on the eve of the big day, the 23d, thanks to the transplant, the beautiful day of solidarity providing cure and complete rejuvenation of your body. Prayers and vision of the perfect fit between the fresh, donated marrow cells and you who will host them. Welcome home to these ? ???

—Isabelle F., October 22, 2018

This primer was so wonderful to read! I learned and was reminded of a lot! Thank you.

I am sending my prayers to those little donor marrow cells that they cozy in and flourish in your body!! Congratulations of reaching this major moment. May you, your donor and your families all feel the love surrounding you!



—Amelie Davidson, October 23, 2018

Holy Guacamole. That was an exhilarating dance through 20th century history. I feel like I just got back from a knowledge-disco. I need a nap.

—John Gastil, October 23, 2018

## Rebirthday

October 23, 2018



**8:00a.m. What lies ahead today.** This afternoon I will receive 3,000,000 or so stem cells donated by a 29 year-old woman from somewhere in North America. Just before the transplant I will have a total body irradiation, the final mode of attack to destroy the remnants of my old immune system. The TBI is especially meant to go after any remaining T-cells, which apparently would attack the incoming stem cells. It is hard not to use military

metaphors here: attack, destroy. I see the remnant T-cells as pirates or Vikings, attacking the peaceful villagers who just want to get on with life.

I begin the day today already tired from the cumulative effects of the the Iomab-B iodine-131 radiation and the fludarabine chemo over the past ten days. The total body irradiation is supposed to add to fatigue, so I imagine I will be pretty wiped out by the time of the transplant. Marcia, Jenny and Becky will be here for the actual transplant, which is pretty much like a blood transfusion, so not a big deal procedure. I will ritualize it a bit, holding hands around the IV pole and giving words of gratitude to everyone who has made this moment possible, especially my donor.

**My image of the new stem cells.** Of course I anthropomorphize my incoming hematopoietic stem cells. They come from a young woman who, it turns out, is ineligible to donate blood to a blood bank, but not to donate stem cells. Why? Because in the past year she has gotten a tattoo or body piercing or visited an "exotic" country, and this makes her ineligible for ordinary blood donations (because blood bank centers can't screen for all the possible infections connected to those events), but the stem cell donations centers can screen for them. She passed. I see her as a tough, slightly countercultural adventurous person who loves life and embraces adventure. I envision her **hematopoietic** stem cells as rugby players, 3 million rugby players milling about in a bag. "What's going on? This isn't isn't a where we should be. Let's scrum!" They wait. The bag gets connected. And off they go, swimming madly into my peripheral blood and instantly homing in to my empty bone marrow. "Wow! Look at these apartments. So clean and tidy and inviting!" So they set up house, and begin the work of building my new immune system. It will be two or three weeks before we have the first real evidence of engraftment as white blood cells first appear in my blood draws. When that happens there will be tests to see if the new cells come from the new stems cells or from my old ones. Hopefully 100% have xx chromosomes. That lies in the future.

### **12:30 pm. Total Body Irradiation**

I was wheeled down for the TBI at 12:30, the final step in the destruction of my Old Immune System and my AML. Well, not quite the final step; my new immune system will have to still do some final clean up work. The routine is that I sit on a bicycle seat in a kind of booth and get 8 minutes of total body radiation first facing forward and then backward. (see the photos below of me and the radiation machine). I am told to wiggle my arms and legs the whole time. They ask me what kind of music I like. I say classical. They have a Sirius subscription and go to the classical channel. It's playing Mendelson's string octet. I don't know it well, but some of the motifs are familiar and it has a regular beat, so I can conduct it while shuffling my feet. All told, an enjoyable 16 minutes.

### **3:00. The Transplant**

I decided that I should slightly ritualize the event rather than just have the bag hung on the pole like a normal transfusion. Marcia, Jenny, Becky and I held hands around the pole. I spoke of how this moment had been the focus of all the hard work we had done since April 4 when I was diagnosed and told that the only way I could survive was with a stem cell transplant. I paid homage to the donor whose kindness and generosity of spirit made this possible. I thanked my body for working so hard to prepare a welcoming home for the new stem cells. I thanked the circles of people who love me, starting with my family and moving out to so many students, colleagues and friends whose messages of love and connection have meant so much. And finally the doctors and nurses at CFAC, and especially the nurses who have made the months I have spent in the hospital a positive

experience rather than an ordeal. There are some pictures and a recording of part of what I said below.

**Later.**

We had a little party with pastries. I could eat the lemon custard in a tart and the filling of a Napoleon (*milles feuilles*). And then I crashed for a couple of hours, happy that we had crossed this threshold, but spent.

**Photos**









## Comments

So glad to read this! So glad to hear that today went ok. The photos are wonderful! Sending much love.

—Gay Seidman, October 23, 2018

Eriki. This is nothing short of remarkable. I'm so in awe of you. I want to figure out how to use this in my teaching. The funny thing is just today when I was giving a lecture in 'sharing information ' with 1st year students, I talked about the value of analogies. I asked who could come up with ones for hypertension or diabetes. Great discussions ensued. And here you are. What brilliance and touching narrative. I'm so proud and impressed and hopeful and sending the 4 of you love and hope. And we're going to talk about how this will get into medical education!!! Love Love and so admire you and Marcia!!!!!!

—Kathy Cole-Kelly, October 23, 2018

So happy and relieved to know that this day eventually happened as a perfect day! thank you so much for sending an update even after such an important and emotional day. We have all been channeling the best energies toward you as the incoming cells are settling down in the best possible environment. Happy re-

Birthday dear Erik!!!!

—Isabelle F., October 23, 2018

A thousand years ago, the Persian poet, Ferdowsi said, "Be relentless in striving for the cause of good / Bring the Spring you must. Banish the winter you should." Happy Super-Duper Re-Birthday, dear Erik! I feel so jubilant that the procedures went very well today! The pictures are just wonderful. The video of the gathering with your beautiful family is so moving and powerful: I broke in tears. Sending you and Marcia and the entire family so much love.

—Masoud Movahed, October 23, 2018

I loved the ritual, such a moving moment. I am so happy this went well and now hoping for all those rugby players to push really hard and win. Abrazo!

—Rodolfo Elbert, October 23, 2018

Hoping everything good in your rebirthday.  
Will be watching your progress. JJ and Betsy

—John Posner, October 23, 2018

Yes, essential and wonderful to thank the nurses and aides and doctors, thank the timing since the clinical trial wasn't available even half a year ago, thank the scientists, thank the donor, thank the loving community of friends, but then let's get down to it. Thank you Erik and Marcia. This has been a non-stop collaboration, based on love but requiring more than love: love plus grace plus grit. 24 hours a day for 6 months. A two person job requiring both people to be filled with fierce determination, patience, humor, and the requisite number of lemon tarts and Napoleons to turn a stem-cell transplant into a party. An honor and a gift to witness what love looks like under some mighty tough circumstances. Love, Ellen

—Ellen Zucker, October 24, 2018

Rik,  
It has taken a village to bring to re-birth a new you. And what a mighty village it is, made of so many ordinary, yet wonderful, individuals both near and far. Your ordinary yet extraordinary life has well earned the support of that village. Carry on Cuz.

Love,  
Wally + + + + + + + + + +

—Wally Rosenthal, October 24, 2018

Happy Re-birthday, Erik! Can't wait to see you Saturday.  
Love,

Vivek

—Vivek Chibber, October 24, 2018

Eriki & Marcia - I love you both and I am thrilled that yesterday happened. Now during this next leg of the journey.... peace, breath, love. Jenn

—Jennifer Wilgocki, October 24, 2018

Very emotional. I'm mentally egging the rugby players on.

—Marianne Ahrne, October 24, 2018

congratulations to you and all those who have helped you reach this day. You may not think of yourself this way, but your ceremony (and the felt need for it) reveal you to be a "religious" person in the deepest sense of the word: where the spiritual as a merely internal experience is insufficient and a community of shared gratitude, love and appreciation of the ineffable wholeness of life is built in order to live more fully. That includes the "rugby players" and adventurous young woman of your present and their past.

—Myra Ferree, October 24, 2018

Sending so much love and care your way!

—Tom Malleson, October 24, 2018

Wow! So amazing that this has finally happened after so much waiting and preparation. Your metaphors helped me to understand both the complex procedure and the immense personal/emotional experience you have all been going through. Love to you all!!

—Mary Jo Maynes, October 24, 2018

Thanks for sharing this wonderful video, Erik.

—Adam Szetela, October 24, 2018

I know you are an enthusiast of classical, but I was thinking this, because to me there is not much better than Bowie and starting a new adventure :) love you guys!

<https://youtu.be/iYYRH4apXDo>

—Heather Crowley, October 25, 2018

## Day 1 post-transplant

*October 24, 2018*

Feeling good. Only real symptom is fatigue, but even that is not of the debilitating variety.

Here is what lies ahead:

It will take my new stem cells about 2-3 weeks to engraft, that is to fully establish themselves in my bone marrow. For the moment I have zero white blood cells and thus zero neutrophils, the component of white blood cells that is the first line of defense against bacteria. I will be discharged from the hospital once my neutrophils reappear sufficiently to provide me with minimal defense.

There are three hazards which I face over the next months of recovery: infection, graft/host disease and a reappearance of leukemia because the remnants of my old stem cells are sufficiently strong to reconstitute themselves. All three of these could kill me, but the head of the transplant team says that they feel pretty confident that they can fully deal with the first two. The biggest threat comes from my old cancer-producing hematopoietic stem cells. We know that they were not completely wiped out by the combination of Iomab-b iodine-131, fludarabine chemo, and total body irradiation. Remnants exist. The hope is that they will be overwhelmed by my new immune system. But since my particular form of acute myeloid leukemia was so aggressive -- really as bad as it gets I was told -- there is no guarantee that they will not push through. This is where the real skill of the transplant team comes into play. They will need to reduce the anti-rejection drugs in order to allow my new immune system to fight the old system, but this in turn risks graft/host disease (my new immune system rejecting my body as a whole). It's all very tricky. I have made it successfully to the transplant, which has been our goal since April 4, but in many ways the most difficult part of the journey lies ahead.

If all goes well, my immune system would be fully back to normal in 10-12 months. I have been told to expect some fevers and infections, that almost always happens, and to expect some side effects from the anti-rejection drugs, like rashes and itchiness. I will take this one day at a time and take things as they come.

One last thing: I have been shaving my head in the shower to keep my bald look super shiny. I decided to stop doing that on my rebirthday. Part of the drama ahead will be to see what the rebirth of my head of hair looks like and how quickly it will come back.

## Comments

Sending you lots of love and strength for the fight ahead!

*—Rachel Schurman, October 24, 2018*

I wish you the best Erik and Marcia. You are both in my thoughts.

—*Mansoor moaddel, October 24, 2018*

Sending much love, Eriki!

—*Gay Seidman, October 24, 2018*

Day 1. What a big day. Thinking of you. -Christine, Christopher, and Clark

—*Christine Schwartz, October 24, 2018*

What a plan of ambush-laden action ahead. You and Marcia are heroic and inspirational! Will be thinking of you with healing wishes, Erik. ????

—*Margaret Somers, October 24, 2018*

You will defeat this, dear Erik! My heart and mind are with you - every hour, every minute! Sending you and Marcia big hugs and much, much love!

—*Masoud Movahed, October 24, 2018*

Sending much love Erik--to both you and Marcia.

—*jeannette golden, October 24, 2018*

You and your family are always in my thoughts and prayers, Erik! Especially as this very major phase of your treatment unfolds. (PS - My mum will be most concerned that your curls return, she was very impressed with your head of hair!)

—*Madeleine Pape, October 24, 2018*

Such a big hurdle now behind you... Thank you always for sharing the experience with us all, pulling us into the circle. Sending much love!

—*Cathy Loeb, October 24, 2018*

So great of you to share the road ahead. Not easy but if anyone can do it, you will eriki!!! Thinking of you and Marcia all the time!!!

—*Kathy Cole-Kelly, October 24, 2018*

We need that head of hair, and more importantly, what lies underneath it, back in soc, Erik. Wishing you and

Marcia continued strength for the journey ahead. Doug & Joan

—*doug maynard, October 24, 2018*

Ciao. I'm so glad you're feeling good and gaining strength for the journey ahead. We had Gianpaolo Baiocchi giving a Cosmos talk, and talked about your work and how to 'erode' capitalism. We missed you. Baci d

—*Donatella Della Porta, October 25, 2018*

## Day 2 post-transplant

*October 25, 2018*

I am dictating this to Marcia. Debilitating fatigue is the name of the game for today. I managed to get out of bed once for a short walk, arms draped on Judy and Marcia. We did one lap of the corridor, 1/8 of a mile, which was absolutely as much as I could do. After that I took a hot shower which felt good but Marcia had to dry me off and apply the anti-bacterial wipes because I had absolutely no energy to do so. After the shower, I staggered back to bed for the rest of the day. The doctors and nurses say this level of fatigue is to be expected, both because of the prior treatment and because of the demands of the new immune system settling in. I'm sure there will be better days ahead.

## Comments

XO. XO. XO.

—*Sarah Siskind, October 25, 2018*

Sending you and Marcia big hugs and much love!

—*Masoud Movahed, October 25, 2018*

Sending our love and warm wishes many times a day, every day, dear friend! xoxo

—*Cathy Loeb, October 25, 2018*

Sending much love to you both.

—Kathy Cole-Kelly, October 25, 2018

Much love! Glad that Judy can be with you and Marcia, so glad you have such a strong network of people who love you!

—Gay Seidman, October 25, 2018

So good that Marcia and Judy can still visit. Somehow I thought you'd be in isolation for a while after the transplant. Hugs to you all!

—Mary Jo Maynes, October 25, 2018

Sending love and hugs to you and Marcia.

—jeannette golden, October 25, 2018

Love and hugs from Belgium. We are with you in spirit and so glad Marcia and Judy can be with you in person as you go through this.

—Judith Leavitt, October 26, 2018

## Day 3 Post-transplant

October 26, 2018

I am dictating this to Marcia. Another day of more or less continuous exhaustion. I managed to haul myself out of bed for my physical therapy class, but it was a really big challenge to be able to do it. There are things I'd like to talk to you about, but they will have to wait until I have more energy so I can write about them myself.

Aside from the exhaustion, I'm feeling okay. And the doctors say that this level of exhaustion is entirely to be expected, so I am not concerned about it.

I don't know what I would do without Marcia here. (Marcia did NOT make up that sentence.)  
I may not write every day until I have a bit more energy, but it doesn't mean there is anything wrong.

## Comments

Erik, I remember that feeling vividly. Could barely move... You're heroic. I'm thinking of you. Xxxx



—Margaret Somers, October 26, 2018

Ok. Take care, both of you.

—Sarah Siskind, October 26, 2018

Sending you and Marcia big hugs with lots of love!

—Masoud Movahed, October 26, 2018

I am v. Relieved the transplant is proceeding according to plan. I am just returning from a two day conference at Goethe Univ in Frankfurt on the occasion of the 40th anniversary of the pub,n. Of KMTH. NBS MG was represented by Philippe, Roberto V. And me. The others were philosophers. Very nostalgic time, lots of stories abt Jerry. Love to you and Marcia, John

—John Roemer, October 27, 2018

Marcia is amazing, indeed! So are you ?. Keep on healin'

—Mary Jo Maynes, October 27, 2018

I'm not really surprised you are exhausted - I trust that your body is hard at work, reinventing an immune system for you! Lots of love to you both.

—Gay Seidman, October 27, 2018

## Day 4 post-transplant

October 28, 2018

It seems that in the morning I have a bit of energy and so can write a little. Yesterday was day 4 post-transplant. The good news is that the doctors enthusiastically say that everything is on track. All of my “numbers” are where they should be. The bad news is that “on track” means another week or so of intense exhaustion combined with various other symptoms. Yesterday nausea was layered onto the fatigue; not severe nausea, more like constant queasiness. So it goes.

There are other things I would like to write about, but this is about all I can do right now.

## Comments

Sending much love!

—*Gay Seidman, October 28, 2018*

Hang in there, Erik, and give us updates when you can.

—*elliott sober, October 28, 2018*

Thanks for keeping in touch, Erik. It means a lot to know you are carrying on. Of course I am curious about the "other things" your wonderful mind is holding, but I can wait. One Love, Jonathan

—*Jonathan Barker, October 28, 2018*

Eriki and Marcia- so impressed you can write even one sentence eriki. Delighted the numbers are on track even if it's a challenging track. Much love to you both!!!

—*Kathy Cole-Kelly, October 28, 2018*

Sending you all the energy I have with lots of love, dear Erik!

—*Masoud Movahed, October 28, 2018*

thinking of you, Erik!

—*Becca Krantz, October 28, 2018*

Thinking of you! We love you Eric .

—*Pauline Thome, October 29, 2018*

Erik, it's so generous of you to keep us posted despite your debilitating fatigue. Thinking of you, Peggy

—*Margaret Somers, October 29, 2018*

Mark and I sending all of our love to you and Marcia!

—*Lisa Reticker, October 29, 2018*

## Days 5-7 post transplant

*October 30, 2018*

A variety of things to report:

### **1. The past couples of days**

Today is the first day in a while that I have had the energy to sit up and write anything. Two days ago was especially miserable because added to fatigue was a bad headache, nausea, and itchy feet. Itchy feet! Whoever heard of itchy feet as a side effect of anything? This is definitely the work of Loki: a mean-spirited joke. While I would not put itchy feet in the same class of misery as nausea and bad headaches, it is definitely above the class of simple "annoying." The itching was especially intense between my toes, so I was constantly wiggling my toes to alleviate the itchiness. It didn't work, of course, but neither did the various creams and lotions the nurses applied. The only relief came with Benadryl, but that was mainly because it put me to sleep.

The doctors' main diagnosis of these maladies is that they were reactions to the anti-rejection medicine. The levels of these drugs are monitored in my blood stream every three days, and the levels appear to be "normal", but still every body is different, and it can take a while for a body to adjust to this drug. In any case today I am free of all three. These kinds of maladies are to be expected, I am assured; they are part of the normal course of developments in the days after a transplant. So far, at least, my recovery remains "on track." I should expect a reappearance of white blood cells in four or five days and neutrophils shortly thereafter.

### **2. Devah Pager**

I received an email two days ago saying that my friend and former student, Devah Pager, had begun hospice care for the pancreatic cancer she has battled for the past two or so years. This is heartbreaking. Devah is an extraordinary person, combining scholarship at the very highest level and a passion for her work with an open-hearted warmth and joyful presence. She lights up a room; everyone feels better in her presence. These past several months she has bolstered my spirits with many cheerful comments to my blog. In my current situation I often think about the possibility of all treatments being exhausted and facing my own death. This, of course, makes me sad, but I have lived a wonderful life of 71 years, I've accomplished a lot, my children are grown and I've met my three grandchildren. Devah is in the prime of life; her son, Atticus in five years old; and she has so much more to offer the world. She will always be in my heart.

### **3. My little brother, Woody**

My brother, Woody (a professor of cell biology at the University of Texas Southwest Medical School), has had multiple myeloma for the past 12 years. Three years ago he was patient #1 in a clinical trial of the CAR-T immunotherapy strategy for fighting cancer in which one's own T-cells are trained to attack the cancer cells, in his case malignant B-cells. The treatment eliminated all signs of the disease for three years. The doctors called this a strong remission; Woody declared to the world that he was cured.

A few months ago, the numbers used to track multiple myeloma began to rise indicating the recurrence of the disease. And so Woody re-entered the world of cancer treatment. The clinical trial was conducted at the

University of Pennsylvania, so he returned to Philadelphia a month or so ago for tests and then treatment. So, at this very moment both my baby brother and I are undergoing treatment for life-threatening blood cancers.

Our treatments, however, are occurring in radically different hospital settings. This was brought into stark relief a few days ago:

*My situation at CFAC in Froedtert Hospital.* I have been here, in residence, since September 1. There have been extended periods when I felt quite well, without any pressing symptoms; and other times when I was miserable in varying degrees. My room in CFAC is spacious, with a pretty comfortable bed for Marcia. The ward is generally very quiet, and at night, my sleep is not disturbed by constant interruptions. When I do get a symptom of concern -- a fever spike for example -- I get immediate attention. I have not for a moment felt stir-crazy or bored; I have felt protected and safe.

*Woody's situation at the University of Pennsylvania.* Woody has mostly stayed in a comfortable hotel suite, with a kitchenette and separate sitting room, a few miles from the hospital. When symptoms emerge, at they did a few days ago when his fever spiked to 102F and he had severe rigors (chills with uncontrollable shaking), his wife Beth was instructed to call the hospital. She did so at 4:00 a.m., but did not get a call back, so she had to keep calling. Eventually she was told to come into the E.R. to be admitted to the hospital. They went to the E.R., a standard E.R. in a big city public hospital. There were no beds available, or even an E.R. cubicle with a recliner, so Woody had to sit in a wheel chair and wait. And wait. Fourteen hours in a wheelchair while feeling completely dreadful. Finally he was given an E.R. bed, and somewhat later moved to a bed in a proper hospital room. No bed there for Beth, so she slept in a chair (I presume a recliner). Woody stayed in the hospital a few days, until everything was stabilized, and then discharged back to the hotel.

I can't imagine in my current state of exhaustion having to sit in a wheel chair for 14 hours. Perhaps for a neutropenic transplant patient at the Pennsylvania hospital, the pattern of in-patient and out-patient care would be different, but still, Woody's immune system is also severely compromised and he is in a phase of his treatments where he can rapidly develop very severe symptoms. I'm sure the actual medical care he is getting is excellent, but the broader physical setting seems much less conducive to low-stress healing. Of course, a facility like the cancer ward in CFAC is much more costly to run than a standard hospital ward, so there are obvious trade-offs. CFAC is also part of a big city hospital open to everyone. My stay is being paid for by Medicare. (My UW health insurance only kicks in for out-patient care). I can't say for sure that in the grander scheme of things, the trade-off is worth the added expense of the wonderful setting in which I am receiving my care; but unequivocally, as a patient, it is worth it.

## Comments

These are such wrenching stories. Thank you for writing.

—Pamela Oliver, October 30, 2018

Dear Erik: I am really sorry to hear the sad news about your brother and Devah. Wishing, wholeheartedly, three of you a full recovery very soon. My heart and mind are with you! Much love -

—Masoud Movahed, October 30, 2018

Am glad the nasty symptoms left off today and look forward to those neutrophils' return. But am also sad about your colleague ... and didn't know about Woody! His news truly sucks. (Other words escape me.) I wish him most well.

—Sarah Siskind, October 30, 2018

It was so great to hear your voice on the phone -- sounding so much like yourself! Hope the itchy feet issue is gone for good.

—Gay Seidman, October 30, 2018

Oh Erik, I am heart broken about Devah. And my full sympathy to your brother. I'm glad you are feeling a bit better today. Here's a tiny glimmer of good news. I went for early voting tonight and an election judge told me that there were 400 people an hour coming through the polling place, with similar numbers in other counties.

—Margaret Vitullo, October 30, 2018

So sorry about Woody. Incredible challenges you both are facing. Hopeful that those white cells are just around the corner excited to build up healthy residences in your blood stream! Sending love always. Xo

—Kathy Cole-Kelly, October 30, 2018

I'm so sorry to hear about Devah and Woody. This is heartbreaking news. It's hard to fathom. Keep writing when you can - the updates are so good to read and I really feel like we are on the journey with you - hopefully giving you a bit of extra love and strength.

—Janeen Baxter, October 31, 2018

So sorry to hear about your brother and the less-than-ideal treatment style. I hope it is effective despite the unnecessary discomforts inflicted upon him. Reminds me to ask how it was that you got connected with the MKE hospital?

I had already known about Devah and find her story as heartbreaking as yours is hopeful. You are right that she lit up a room and her personality was just as exceptional as her work. Wish I had had a chance to get to know her better in the year or so we overlapped.

—Myra Ferree, October 31, 2018

## Day 8 post transplant

October 31, 2018

I was officially declared by the I.D. Team (infectious diseases) to be a boring patient, not to be confused with boring person. Being a boring patient is a much sought-after declaration. I.D. was called in because my BMT team (bone marrow transplant) had decided that my PICC line (peripherally inserted central catheter) needed to be switched from my left arm to my right arm because of the appearance of some red, tender inflammation around the line's insertion point. That happened this morning: I was taken down to I.R. (Interventional Radiology) at 9:00 to have the PICC line removed from my left arm and a new one inserted into right arm. As far as quasi-surgical procedures go, this is pretty tame — a lidocaine shot into the inside of your upper arm, followed by the insertion of a hollow wire into a vein through which the actual PICC line is then threaded. Pretty straightforward, except they had to do two tries since in the first attempt my vein spasmed and so they could thread in the line. I.D. Then came to see me. Since I had no fever, and the old PICC line sight didn't look infected, they said that it was very unlikely that the tip of the PICC line, which has been sent to the lab to be cultured, would show anything. And since I had not had any fever for a month, and nothing after the transplant, I was at this point a boring patient.

The endocrinology team, on the other hand, see me as a VIP (Very Interesting Patient) since my D.I. (Diabetes insipidus) seems to have really disappeared. I reported this earlier, but a bit prematurely, since symptoms did return and so I had to use the artificial hormone delivered by my desmopressin spray. What happened was that the length of time I could go without symptoms steadily increased from 17 hours to 24, then for a while around 30-35. It has now been over 80 hours. The endocrinology team started taking urine samples to test for what they call the urine's "specific gravity", which is some sort of measure of its concentration. With untreated D.I. the urine becomes very dilute. The artificial hormone from the desmo nasal spray last for about 12 hours, so after 24 hour for sure I am effectively untreated. My specific gravity was normal at 60 hours! The head of the endocrinology team is pretty certain this means that I am now free of diabetes insipidus. They will continue to take measurements, including a measure of the presence of the relevant hormone in my blood, so that they can write up a case report on me. I will be a Published Patient, not to be confused with a patient who publishes (which I am also), which definitely means I am not a boring patient but a VIP.

### **A coda on my report about my brother Woody.**

In spite of his miserable experience in the ER a few days ago, he is now doing extremely well. It seems like the new round of CAR-T treatment is working. He feels good and feels that everything is on track for him to return home in a week or so.

### **Something super-interesting for anyone in the Philadelphia Area**

I want to encourage anyone in the Philly area to see a performance of the latest play directed by my daughter Becky and written by her husband, Adriano. I won't be able to see it, alas, but the reports I have received from people who have seen it is that it is nothing like any other play they have ever seen and that it is really wonderful. Here's the deal: For most performances only 1 ticket is sold; 1-4 people can see the performance on that ticket. These tickets cost \$100 or, if you want drinks and edibles, \$200. Here is the description from the website where you can buy tickets:

*Perfect Day is an intimate performance experience. It may be viewed alone, in pairs, as a group of three, or a party of four. Perfect Day is not frightening or confrontational. Perfect Day does not depict*

conflict, or invent any drama. *Perfect Day* provides you with luxury seating posture and a delightful story about people getting what they want.

For guests who wish to view *Perfect Day* in mixed company, we offer four individual \$25 tickets for Wednesday and Thursday evening shows. On Friday, we offer two \$100 performances for you to enjoy alone or with up to three guests of your choosing. Come Saturday night, *Perfect Day* costs \$200 for one performance (for you to enjoy alone or with up to three guests of your choosing) and includes additional deluxe treatment. (There are also a few Sunday shows, at different price points.)

Here is the ticketing link: <https://perfectday.brownpapertickets.com/>

If any of you go, I would love to hear what you think.

## Comments

Amazing about the DI - well done, Erik! Definitely a VIP in my book. :)

—Cathy Loeb, October 31, 2018

The news is just getting better and better (both for you and your brother), dear Erik! I think the endocrinology team should not forget mentioning in the report that you are also a Very Inspiring Person (VIP)! Sending you and Marcia big hugs and much love!!

—Masoud Movahed, October 31, 2018

So good to get these updates, Eriki (and Marcia)! from boring to not boring to VIP to published all in one posting! And the good news about Woody and about Rebecca and Adriano's latest production. Sounds like a perfect day all around.

—Mary Jo Maynes, October 31, 2018

Eriik:

You must be feeling good -- all that humor and punning in your post. Onward!

Bobbie

—Barbara Marwell, October 31, 2018

We love VIP and boring patients! You rock! As ever, sending love and peace of mind.

—Isabelle F., November 1, 2018

Great news! Onwards and upwards.

—Emanuel Ubert, November 1, 2018



## Day 9 & 10 post transplant

*November 2, 2018*

### **The story of scrambled priorities of a bedraggled bone marrow transplant patient**

#### *The Cast of Characters*

Erik: the patient

Marcia: the patient's very sensible, diligent CEO

The endocrinology team (ET): very smart doctors and fellows who know a lot about hormones

#### *Wednesday, October 31.*

Two members of the Endocrinology team, including the head, visit Erik's room. Erik tells them that it has been over 90 hours since his last dose of desmopressin to treat his diabetes insipidus. Everyone is delighted. "Doesn't this mean that the d.i. is gone?" Erik asks. "It looks that way," the ET head replies. "This deserves as case report," she adds. She decides to gather more specific data on the specific gravity of my urine and the presence of the Vasopressin hormone (the hormone missing in d.i.) in my blood. This is all very interesting. Erik is really into the idea of becoming a case report.

#### *Thursday, November 1*

The symptoms of diabetes insipidus slowly return. Erik is peeing every hour and a half to two hours. Erik is disappointed. The ET return. "Maybe this will resolve itself," they speculate. "Can you hold off on taking the desmopressin nasal spray?" "Sure," Erik eagerly replies. "I'll keep a pee log and we can see what the trend is." "Well check back tomorrow," says the ET team.

Pee log: 8:25 a.m., 9:45, 10:42, 11:30, noon, 1:35, 2:40, 3:50, 4:50, 5:05, 6:25, 7:35, 8:45, 9:45 pm.

Time for bed. Marcia: "Eriki, you really should take a dose of desmopressin to get a good night's sleep". Erik, "I'd rather keep going with the experiment. I'll talk about it with the ET tomorrow." So the Pee log continued: 11:20, 12:10, 1:45 a.m., 2:25, 3:35, 4:15, 5:45, 6:40, 7:20, 8:10, 8:50. Even with a bedside urinal, that is a lot of sleep disruption. In the morning Erik was exhausted. For some reason, he was surprised about this since the day before he had felt a bit more energetic. "Eriki, what do you expect? You were up every hour to pee." Erik relented and took a dose of desmopressin and fell right back to sleep. At 11 he went to his PT class. At noon he went back to sleep and slept until late afternoon when the nurse came in to give him a unit of red blood cells. When the ET came by they thought it was a good idea. Now he is reasonably peppy.

The moral of the story: *Listen to Marcia.*

## Comments

So, a husband acknowledging the wisdom of his wife! Excellent chuckle. I sure understand the passion to do the experiment , though. Beautiful clear night in Lake Monona tonight - had nice Fall walk on Morrison Street. Trees that have lingered in green finally changing - I think I heard a news article said they were so green for so long because of rain this Fall. The body of nature and the body of the human being are so amazing in finding their balance. I holding an image of you regaining your balance, as your body finds its way to its innate wellness. xo Jody

—Jody Whelden, November 2, 2018

So, a husband acknowledging the wisdom of his wife! Excellent chuckle. I sure understand the passion to do the experiment , though. Beautiful clear night in Lake Monona tonight - had nice Fall walk on Morrison Street. Trees that have lingered in green finally changing - I think I heard a news article said they were so green for so long because of rain this Fall. The body of nature and the body of the human being are so amazing in finding their balance. I holding an image of you regaining your balance, as your body finds its way to its innate wellness. xo Jody

—Jody Whelden, November 2, 2018

Sending you and Marcia big hugs and SO MUCH LOVE!! My heart and thoughts are with you, dear Erik!!

—Masoud Movahed, November 2, 2018

Indeed?!

—Mary Jo Maynes, November 2, 2018

Moral of the story Bis: Nothing can divert a scientist from a good experiment!!! You rock! But probably a good idea to keep your energy for the worthy fight :-)

—Isabelle F., November 3, 2018

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—Isabelle F., November 3, 2018

Sandy and I sending lots and lots of love!!!

—jane mansbridge, November 3, 2018

I just head about Devah. So heartbreaking. So glad you are better.

—Emanuel Ubert, November 3, 2018

## Day 11 & 12

November 4, 2018

These are days forecast by the head of the bone marrow transplant team as being the worst. I have slept almost continuously for two three, getting up mainly to take pills, pile and piles of pills, giant pills, tiny pills, pills in lovely multicolored casings, stupid monsters pills that have rough chalky surfaces making them hard to swallow. Morning pills, noon pills, evening pills and pills in between. And the piece de resistance: the Lovenox shots I give myself in the belly. I have had mild nausea and headaches most of the time these past few days, and last night I had a fever. Aren't I pitiful? But the doctors say these maladies are entirely to be expected and nothing to worry about. So sleeping all the time is a good thing.

\*

As many of you probably already know, Devah Pager died two days ago. This is heart breaking for everyone who knew her.

## Comments

I am with you Erik in spirit, hang in there, and may the force be with you.  
With lots of love and affection for you and Marcia

—Mansoor moaddel, November 4, 2018

Sending good vibes, big hugs and much love to you, dear Erik!

—Masoud Movahed, November 4, 2018

I love these reports. Sleep is No. 1!!

—Sarah Siskind, November 4, 2018

Hang on in there! Sending love!!!!!!!!!!!!!! - Jenny & Sandy

—jane mansbridge, November 4, 2018

Sending lots of love and hugs from Buenos Aires. Abrazo

—Rodolfo Elbert, November 5, 2018

So the doctors feel that these maladies are to be expected and nothing to worry about. Well, if any of them were enduring these symptoms, I would find it easier to accept their advice: I wouldn't worry about it.

—Robert Kahn, November 5, 2018

Just a short note to say I'm following your progress, wishing you the best, and learning (as ever) from your positive outlook.

—Seana Shiffrin, November 5, 2018

Erik you are a trooper! Keep it up!

Thinking of Devah today. And of you.

—Matt Vidal, November 5, 2018

## Day 14 post transplant

November 6, 2018

### **CNN, breaking news, Milwaukee**

The numbers are in: neutrophils make their first appearance. There have been hints of neutrophils for several days as we have seen some monocytes floating about, since in normal times monocytes mature into neutrophils, but today is the day we have a positive number to report under the Absolute Neutrophil Count (aka "ANC,"

neutrophils per cubic millimeter): 40. There's still a long way to go until Erik will be declared no longer neutropenic -- 1,000 -- and a bit longer before he is in the normal range of 1500-8000. But it is a start. Once he is above 500 for two days in a row he can be discharged from the hospital, where he has been for over two months. Let's now go into the field where our in-body reporter is ready to interview one of these newly minted neutrophils.

Reporter: Tell me, what's it like being a brand new neutrophil in Erik's body?

Neutrophil: It's great. I'm feeling right at home here. It's nice to get out of the bone marrow and into circulation. The bone marrow was fine, but it's a bit claustrophobic. So, it's good to leave the nest, get out into the world and begin doing our job. Everyone's excited.

Reporter: There's only 40 of you per cubic millimeter. That must pose some big challenges.

Neutrophil: You're right about that. This poor boy has been without any neutrophils for a long time. We can tell that he's loaded down with antibiotics. They've done a good job -- I'm not knocking antibiotics -- but they really aren't a substitute for us. No way. I see that there is a lot of cleaning up for us to do. I have hardly any time for rugby practice, but I've got my priorities straight: protect this body from perils diverse. Uh-oh....I can't talk for a while

Reporter: What's up?

Neutrophil: I'm about to divide.

Reporter: This is quite amazing. We're right here on the front lines watching a young neutrophil divide. Yes, that's what's happening. It's pretty fast.

Neutrophils (in unison): Ah, that's better. When you gotta go you gotta go.

Reporter: I just have one other question: what's it like being female neutrophils in a male body?

Neutrophils: Makes no difference to us. We gotta job to do and we do it. XX or XY, makes no difference. Well, we have to get back to work. Nice talking to you.

Reporter: Well there you have it. Young neutrophils, produced by the transplanted hematopoietic stem cells, working hard.

## Comments

I enjoyed this. Hang in there. You have a lot of people who care about you.

—*Pamela Oliver, November 6, 2018*

Wow! Wow! Wow! ;-) :-) :-) Go Neutrophils! Maybe they should be called Neutrophilippas?

—*Mary Jo Maynes, November 6, 2018*

Great news!

—*Annabel Ipsen, November 6, 2018*

Well done Rik! Much better than the CNN on my TV. I read your entries religiously (or, atheistly). You write very well.

It seems that you are doing very well. A bunch of Canadians are thinking of you. Love, Peter

—*Peter Rosenthal, November 6, 2018*

Nothing short of brilliant Eriki!!!

—*Kathy Cole-Kelly, November 6, 2018*

Nicely put-short, effective, and truly amusing.

—*Mansoor moaddel, November 6, 2018*

Great interview! Great news.

—*Sarah Siskind, November 6, 2018*

Go neutrophils!!!! Great job of reporting, too. And one hell of a sense of humor. Many hugs - Jenny & Sandy

—*jane mansbridge, November 6, 2018*

Amazing neutrophilippas ... and wit! Huge hugs, Julia

—*Julia Adams, November 6, 2018*

Jaws drop in admiration of your lucidity and diction in reporting, dear Erik! So delighted that the neutrophils are doing a great job! Sending you and Marcia big hugs and much love!

—*Masoud Movahed, November 6, 2018*

## Day 15 post transplant: scientific corrections to neutrophil interview

*November 7, 2018*

I stayed up late watching the Wisconsin elections returns, which weren't finalized until a bit after 1 a.m., so naturally I am a bit tired today. But this morning's tiredness is the familiar day-after-election tiredness from not having quite enough sleep rather than the neutropenic deep fatigue of being sleepy because of lack of neutrophils. What a difference! Given that the Wisconsin results were so good, there is even something a little sweet about being a little tired. Today I have no trouble sitting up and writing and carrying out normal activities; with the neutropenic fatigue that just wasn't possible. My ANC today is 120, triple what it was yesterday. And zero blasts, indicating that these neutrophils are very likely entirely from my new immune system. My platelets and red blood cells are also up without the aid of a transfusion, a sure sign of engraftment. So, on all fronts, I'm definitely on the road of recovery.

### **CNN Special Report, Milwaukee.**

An attending physician at the Center for Advanced Care learned of the interview with a neutrophil yesterday and was shocked by the scientific errors, some of which call into question whether or not the interview actually took place. We feel obligated to correct the errors. The reporter has been fired.

1. Neutrophils only divide when they are still in the bone marrow, so the reporter's claim that his interview was interrupted by the neutrophil's cell division is absurd since the neutrophil was in the peripheral blood rather than in the marrow itself. Neutrophils divide in the marrow and then spill into the blood stream to do their work.
2. Once in the blood stream, neutrophils only live for about five hours during which time they are frenetically busy. It is therefore ridiculous for the neutrophil to talk about rugby practice. Of course there is no time for rugby practice, but there would also be no time for rugby. All rugby played by neutrophils occurs in the bone marrow, not the blood stream itself. This is a well-known fact.

## Comments

You are amazing!!!

xxx

*—Janeen Baxter, November 7, 2018*

So happy to hear of the progress. Wonderful!

As to the reporter-- it is now obvious that he should not quit his day job.



Sending love to you and Marcia

—*jeannette golden, November 7, 2018*

Your humor in the face of everything you have experienced is amazing. Your spirits seem to be on the upswing, along with the neutrophils.

Thanks for keeping our spirits up as well. And Scott Walker's defeat only adds to the joy.

—*Barbara Marwell, November 7, 2018*

I am thrilled and tickled hearing the good news from you and the Wisconsinians who did the right thing yesterday.

—*Mansoor moaddel, November 7, 2018*

This is the very best news of all!

—*Cathy Loeb, November 7, 2018*

Glad to hear this good news!!!!

—*elliott sober, November 7, 2018*

SO glad that the recovery is going smoothly! I am delighted that those little neutrophils are hard at work, we are all deeply grateful to them! Really, taking care of Eriki is waaaay more important than rugby, I am glad they understand that.

—*Gay Seidman, November 7, 2018*

Yay on all fronts - medical and political! (I kind of liked that reporter, even if the part about rugby was fake news :-))

—*Mary Jo Maynes, November 7, 2018*

So happy to hear the good news! We're rooting for those neutrophils, whether or not they have time for rugby!

—*Loren Peabody, November 8, 2018*

Great to read your recovery is going well!

—*Adam Szetela, November 9, 2018*

## Day 16 post transplant: odds & ends

*November 8, 2018*

### 1. The Art of Phlebotomy

For the past three weeks or so I have had a blood draw every 2-3 days via a direct poke rather than via my PICC line. This was needed to test the level of the key anti-rejection drug in my blood. It tends to concentrate around the PICC line so you can't get an accurate reading from blood taken via the line. No one likes shots. I think that even when you are used to them and get blood draws regularly, there is still a bit of apprehension when the phlebotomist enters the room with the paraphernalia of the trade. At Froedtert Hospital there is one phlebotomist, Etienne P. (I don't know his family name) who has such fantastic technique that when he arrives I greet him with pleasure and no dread. He's older than most people in his role -- in this 50s -- and I think from Haiti judging from his lovely accent. He explained to me how he does it: "It is all in the fingers." He shows me the motion of thumb and index finger touching at the tip and moving back and forth. "Most phlebotomists use their arm muscles to push in the needle. I tell my students that pushing a needle into a vein is like threading a needle -- you just use your fingers. I have them practice by threading a needle. They practice this outside of class to get the signals between the brain and the fingers re-enforced. You line up the needle with the vein and the thread it. And as soon as blood comes out, I stop." Today I literally did not know when he had done the procedure.

### 2. Strange, interesting dreams

My dreams from last night are quite vividly remembered. In the dreams I was writing short stories. I worked on three. I am used to writing in my sleep when I'm working on academic papers, but I don't remember writing short stories. I suppose this was stimulated by my tale of rugby neutrophils. I didn't finish any of the stories, but here are sketches of what they were about:

#### #1. *Cheating at poker.*

*The setting:* The Old West, in a settled town probably in Colorado in the 1880s; in the parlor of a fairly fancy house.

*The story:* The family in the house were avid poker players and invited strangers to play with them on occasion. Pretty high stakes -- thousands of dollars a night. When they played just as a family they used a deck with marked cards so that Grandpa, who was a bit senile, could occasionally win. In the corners of the cards were tiny markings like AS for ace of spaces or 9D for nine of diamonds. They never used the marked cards when strangers were in the game;

this was strictly for the low stakes nickel-dime poker they played with Grandpa.

Well somehow the deck with marked cards was used one evening when a high stakes game was being played. The stranger was a professional poker player who went from town to town to clean out the locals. After losing the first four or five hands he began to be suspicious and easily figured out what was going on. He then began holding his cards in a way that no one else could see the backs of the cards and won big. At the end of the night one of the family members accused him of cheating. [that's where the story ends in the dream].

## *#2 Victorian traveler.*

A wealthy Victorian-era British woman spends all of her time living on ships going from one port to another mainly in South Asia, Southeast Asia, and East Asia. She is an avid reader and spends all her time on board reading. To keep a good supply of books, she has a crate shipped from England waiting for her at every port. She is fluent in French, German, Italian, and Russian so that she will never run out of things to read. She arrives in Singapore, but there is no crate of books waiting for her, so she goes ashore to buy books and gets lost in the city and eventually kidnapped. [that's where the story stops]

## *#3 French inspector of small dams*

The story takes place in the present. The first person narrator of the story is the Chief Inspector of Small Dams in France. He talks about his job and how wonderful it is to inspect all of the small dams in France, some of which are centuries old. The narrator talks about how some very old dams no longer work -- they have no working flood gates -- and have basically just melded into the landscape. The narrator expresses concern because there has been an increase in dam failures, causing severe flooding. He is trying to figure out why this is happening. Meanwhile Loki (Norse trickster) and Hermes (Greek trickster) have teamed up to transform the countryside of France by mucking about with the small dams. They have a magical super-detailed map of France and when they put an x through a small dam, it freezes up or disappears completely causing floods and either creating new lakes or making lakes disappear. [That's as far as I got with the story.]

These really were stories I was writing in my dreaming last night. I have no idea what the subconscious roots for the three different themes might be.

## **3. What my new immune system is accomplishing**

On October 23rd when I had my transplant, I had no white cells. An average person has somewhere around 50 billion white cells (around 8,000 per microliter; the average human body has about 5 liters of blood). About 50-60% of these are neutrophils, so let's say roughly 25,000,000,000. They live for only 5 hours. So, the new hematopoietic stem cells now constituting my bone marrow have to produce sufficient white blood cells to deal with a turnover of 25 billion every five hours. My current level of neutrophils is 250 per microliter, which would mean about 25 million neutrophils in my body. This needs to be increased 1000-fold to be in the middle of the normal range. It's all pretty amazing to me.

## **4. CNN, November 8, Milwaukee**

After receiving a number of protests over the firing of our in-body reporter as reported yesterday and careful consideration, she has been rehired. The distinguished Colombian Sociologist Tatiana Alfonso made the most compelling argument: "Medical error in media reporting is a constant! Don't fire the reporter; enable her to learn science." We will create a science education program for all our reporters. Before we send her back into the field, we will also make sure this reporter understands the fundamentals of rugby so she can report on some of the rugby matches in the bone marrow.

## Comments

Sending you and Marcia so much love, dear Erik!

*—Masoud Movahed, November 8, 2018*

I'm glad that protests were heard and the reporter rehired. I like the 3 storylines, but don't have a clue about what if anything connects them to each other or your brain :-)

*—Mary Jo Maynes, November 8, 2018*

Glad to see that the transplant is working. JJ

*—John Posner, November 8, 2018*

such interesting stories. i hope you dream the next installments.

*—Robert Kahn, November 9, 2018*

## Day 17 post transplant: soon to be discharged

*November 9, 2018*

It looks like I will be discharged from Froedtert on Sunday, November 11. Here's our plan: The first night we will spend at the Marriott Residence Hotel across the street from the hospital. Monday we will move to *Kathy's House*, a facility for family members and patients, for a few nights until the apartment, five minutes away from the hospital, which we will be renting until the end of December is available. That should be by Wednesday or Thursday.

I thought this would be a good time to take stock of New Life Experiences that I have had since being diagnosed with acute myeloid leukemia in early April. Here is my provisional list.

### **New Experiences since April 2018 because of AML (not all at the same time)**

- 1. PICC line.** There have been some occasions -- like when I spent a night in the hospital after being hit by a car in 2015 or when I had a heart attack in 1993 -- when I have been attached to an IV pole, but I have never had a PICC line installed to deliver drugs and to draw blood. I love my PICC line.
- 2. More than a few days straight in a hospital -- ten weeks as of November 9.** My hospitalization this fall has been the longest by orders of magnitude. I am ready now to leave because I am feeling well, but at no time during my hospitalization did I feel "stir crazy" or want to be anywhere else. Here I felt safe, protected.
- 3. Depth of exhaustion, fatigue, tiredness, day after day.** The levels and quality of fatigue I have experienced, especially in recent weeks, is like nothing I can recall in my life. Fatigue that restful sleep does not abate.
- 4. Abrupt exhaustion.** This is different from just the depth of exhaustion. There are times when I suddenly feel completely depleted -- like a car running out of gas. One moment, chugging along just fine. Then, nothing.
- 5. Mountain of pills to take every day -- over 50 a day.** Endless pills of all description. A few of them have really unpleasant casings.
- 6. Night sweats -- up to 9 t-shirts drenched at night (these ended a month ago!).** For many months, my sleep was continually disrupted by wet t-shirts. I would sleep with a stack of fresh t-shirts next to my bed. That suddenly stopped at the end of September, before the final conditioning that destroyed my bone marrow.
- 7. Being bald (while not being a baby).** I have always been a bit vain about my head of hair, but also curious about what I would look like bald. Just before the conditioning phase of the treatments when I would have lost most of my hair anyway, I decided to shave it all off. It's been fun being bald, even though I still don't recognize myself in the mirror. I've now stopped shaving it off in the shower every night, so it is growing back. I love when Marcia strokes my head now. With just a stubble of in-coming hair, the feeling is wonderful. It is also noisy, a kind of fluttery-buzzing sound as heard from inside my head.
- 8. Taste buds completely screwed up.** Almost everything tastes terrible. It is hard to describe the character of the distaste. My mouth is covered with a gummy metallic tasting coating, and when I eat something this gets intensified with saliva and makes the food unpalatable. As a result my diet is mainly liquid -- protein-fortified milkshakes and Glucerna (a high protein drink like ensure, but less sweet) -- except for cheerios which I can eat if I let it get real soggy. It is hard to get enough calories just from the drinks, so I've lost almost 20 pounds since April. I'm told that this issue will slowly resolve itself; there is nothing special to do about it.

- 9. Rigors (severe shaking with a fever spike and chills).** This only happened once in April, but is really a terrible feeling.
- 10. Attached to IV pole day-after-day.** My IV pole is named Pola. She's been very helpful, but it is time to say good-bye.
- 11. Bone marrow biopsies.** The first one was very painful, but tolerable. Then Janet (my sister-in-law, Marcia's sister) gave me a guided meditation to control pain and what a difference that made.
- 12. Blood transfusions to raise hemoglobin and platelets.** I've had blood transfusions, of course, but never as every other day occurrences. Now it seems this may be over since my new hematopoietic stem cells seem to be producing plenty of platelets – they are now at a normal level! – and even red blood cells. So, no more transfusions, for a while anyway.
- 13. Showers beginning with a press & seal wrap and ending with sticky CHG wipes.** I take a shower here almost every night. In preparation, my PICC line arm needs to be wrapped to prevent water getting on the PICC line insertion point dressing. Wrapping consists of three layers of press & seal (sort of a sticky saranwrap), and tape at the wrists and upper arms and along the seam of the wrap). After the shower I have to be wiped down with anti-bacterial wipes that leave a slightly sticky residue. The shower here is lovely, but these book-ends make it a chore rather than a pleasure.
- 14. Not going outside for weeks and weeks.** I would have thought this would have been annoying, but it hasn't been. I have been happy just staying in my nest in CFAC.
- 15. Vitals every four hours and orthostatic vitals (lying down then standing up) once a day.** I guess it is standard operating procedure in hospitals to take Blood pressure, oxygenation monitor on finger, and temperature every four hours. I don't mind much, even in the middle of the night. Generally the nurses here take my midnight vitals at 11 and my 4a.m. vitals at 5:30, so my sleep isn't too disrupted by that.
- 16. Waves of dark emotional intensity that hit suddenly without always any obvious immediate trigger.** This has been one of the most unsettling experiences for me. This usually happens when I am physically depleted, but not always. I describe the experience as being hit with an intense wave of dark emotions, not as a gradual build up or slide into sad feelings, but as engulfing, overwhelming feelings. As I experience this, there is no obvious trigger or focus, but Marcia feels that there often is some kind of trigger. Yesterday, for example, I ordered what was described as roasted zucchini and squash, thinking that this would be easy to eat. It turned out to be pretty heavily seasoned, and when I smelled it I knew I couldn't eat it, and I burst into tears, but was also filled with these intense dark emotions, emotions filled with grief and despair. This generally passes quickly; it doesn't settle in. But it always leaves me unsettled. It is not surprising, of course, that someone with AML would have dark thoughts and despairing emotions. What is new to me is being abruptly slammed with such feelings.
- 17. Ten weeks, 24/7, with Marcia in one room.** I have never spent 10 weeks, 24 hours a day, with Marcia in a cozy room together (except for a very few days when Marcia went to Madison for the day). It has been

wonderful, totally wonderful. We've been together 53 years – we met on a blind date in late October, 1965 – and married 47. If I had been asked before I was sick if Marcia would have been this wonderful, I would have said yes, but I wouldn't have fully, deeply, understood what that meant. Now I do.

## Comments

"I am ready now to leave because I am feeling well...." Many wonderful things in tonight's post, but this is the very best. What an amazing, blessed turnaround! And so happy that one of the apartments near the hospital is becoming available! Big hugs, Cathy

—Cathy Loeb, November 9, 2018

Amazing and moving -- what a combo of analytic distance and internal depth! Whew. Sandy and I rejoicing both that you are leaving and that you had exactly the right cocoon in which to begin to recover. A million gazillion hugs and love -- Jenny

—jane mansbridge, November 9, 2018

It is hard to read this without shedding tears for anyone who knows you, dear Erik! Sending you and Marcia all the love I have - I am so delighted that you are feeling better and that you are soon going to be discharged from the hospital. Big hugs and much love!

—Masoud Movahed, November 9, 2018

This is such an intense post to read. So good and true at the same time. Almost too good to be true, yet it is!! I need to shout Yahooooooo, you are making it!! You rock, dear Erik!!!!!!! Sending continuous love and prayers, i.

—Isabelle F., November 10, 2018

Wow. Just wow.

—Stefan Svallfors, November 10, 2018

Eloquent and moving provisional summary! So glad you had such a safe place to be--and even more glad that



you're headed out!

Love,  
Sonia

—Sonia Baku, November 10, 2018

## Day 18 post-transplant, morning: Success!

November 10, 2018



Yesterday midday I gave myself a shot of neupogen, a drug that stimulates the bone marrow to ramp up its production of neutrophils. The idea was to get me above 500 neutrophils per micro liter, the threshold for discharge. Yesterday my number was 290. This morning's number: 3,900. Unbelievable. The normal range is 1,500-8,000, so I am smack dab in the center of normality. The level of neutrophils won't stay this high, but is still likely to settle down above 1,000.

This neutrophil level definitively confirms discharge from the hospital. The plan is for discharge Monday morning. We will then move for a few days into a place called Kathy's House which rents rooms to patients and families who need short turn accommodation near the hospital, and then move to a proper one bedroom apartment owned by the hospital later in the week. We will be there for the next 60 days or so.

For the moment I am feeling very good and peppy. Since I am now eligible for discharge (even though I will stay here for two more days since Kathy's house is full until Monday), I have been unhooked from the IV. It is wonderful to be untethered -- to walk freely and not get tangled up in tubing. Below is a photo of me freed from Pola, the IV Pole.

So, next week I will be out in the world, entering the next chapter of this saga. I am not really out of the woods -- there are still real hazards ahead: infections, in spite of my happy neutrophils; graft/host disease, in spite of my perfect match with the donor; and a resurgence of the leukemia, in spite of the grand efforts to eradicate it with radiation and poisons before the transplant. The last of these is the most serious risk; as the head of the transplant team cheerfully said, "if anything is going to kill you it will probably be a leukemia relapse." Almost for sure remnants of my defective stem cells still exist. The hope is that they will be overwhelmed by the new immune system, but that is a hope rather than a certainty. I feel I have come a long way and been through a lot, and I am feeling happy and optimistic about what lies ahead. I don't worry (much) about relapse, but it is a possibility. I am determined for that possibility in the future not to intrude on my life in the present.

## Comments

Wonderful! Such a good news. Definitely no relapse.

—Lefeng Lin, November 10, 2018

Fantastic, Eric! xo, d.

—David Griffeath, November 10, 2018

Sharing and delighting in the joy!

—Cathy Loeb, November 10, 2018

Congratulations on your neutrophils and your impending discharge. " You've come a long way, baby". With love, Bobbie

—Barbara Marwell, November 10, 2018

Go, Erik!!!! Go neutrophils!!!! Love, J & S

—jane mansbridge, November 10, 2018

Hooray! Hooray!!

—Mary Jo Maynes, November 10, 2018

Hooray!!! Fantastic news, dear Erik!!! So much love to you and Marcia -

—Masoud Movahed, November 10, 2018

Congratulations, Erik! What great new! Hope to see you soon back in Madison.

—Chaeyoon Lim, November 10, 2018

We look forward to having you back in Madison in January !

—Pauline Thome, November 10, 2018

We look forward to having you back in Madison in January !

—Pauline Thome, November 10, 2018

Excellent. In every way. Love to Marcia.

—Sarah Siskind, November 10, 2018

So great to see you in such great shape today! And to see that your hair is growing in — still curly!!!

—Gay Seidman, November 10, 2018

Great news, great smile! And intriguing tshirt.

—Myra Ferree, November 10, 2018

So glad you will be free of the tubing and out of the hospital! All sounds positive! Love to you and Marcia, Eve and John

—Eve Silberman, November 10, 2018

Wonderful news for now! Sending so much love!

—Amelie Davidson, November 11, 2018

Eriki, you look and sound great- and I love your t-shirt! So glad you are continuing forward, positive movement and discharging Monday. We hope to visit next weekend if possible. Love you so much! Lisa, Sam, Ella, and Maya?????

—Lisa Baker, November 11, 2018

Wonderful news, I'm so happy for you Erik. The Jewish prayer, Amidah, recited daily, 2500 years old, has 19

parts,

and Amidah #8, for healing, allows a supplication for one person, and in addition to reciting let me post it here.

Heal us O Lord, and we shall be healed, save us and we shall be saved, for thou art our praise.

Grant a perfect healing to all our wounds,

AND A PERFECT HEALING TO ERIK,

for thou, almighty King, art a faithful and merciful Physician. Blessed art thou, O Lord,  
who healest the sick of thy people Israel.

*—Hal Gabow, November 11, 2018*

congrats, Erik!

*—Matt Nichter, November 13, 2018*

## Day 20 post transplant: discharge day!

*November 12, 2018*

**Noon, November 12.** Waiting in 8CFAC room 9 for the pharmacist to come by a go over all of the many many pills I have to take, then we're out of here. Two and a half months is a long time in a hospital room. It has been a good place to be, enjoyable under the proverbial circumstances. But now I'm ready to go and start the next chapter.

**7pm, Kathy's House.** I'm out in the world. I breathed fresh air for the first time since early September — cold, crisp, wonderful Wisconsin autumn air. At 2pm we drove to Kathy's House, a facility for families and patients at Froedtert. We have a pleasant, comfortable room and access to a fine communal kitchen. I think this will be excellent as the interim place for us to stay until the apartment is ready sometime in the next four or five days. And the biggest surprise of all: this evening I had a proper meal, much to my pleasure and astonishment. The first real meal in about two months. Kathy's House does not normally provide meals, but tonight there was a special pre-Thanksgiving Thanksgiving dinner — turkey, stuffing, gravy, mashed potatoes, cranberries — provided by volunteers. I suppose there was a small risk involved in actually eating it, but we were told I could now eat at "reputable" restaurants, and we figured this was a close enough facsimile. Before dinner, as suggested by the doctor today, I brushed my tongue with a tooth brush and had an anti-nausea pill just in case. And lo & behold: I could actually eat the food.

So now we enter a new routine. We have to sort out the 40 pills I take a day (I asked the pharmacist and he counted them) into the times when they need to be taken. Marcia bought a giant pill tray to help us out on this.

And we need to organize the day to allow for some gradually increasing exercise. Once we are in the apartment I will join the gym that Marcia joined — she has been swimming half a mile almost every day! — and do some strength training and mild aerobic workouts. Clinic visits will be three times a week. This will be the routine until everything goes haywire with a fever or a symptom of host/graft disease (rashes, nausea, etc.). These happen to roughly 90% of patients who then require brief re-hospitalizations. We'll try our best to be in the 10%.

At the moment I am feeling very happy to be out of the hospital, as much as because of what this signals — that I am on track — as because of the physical pleasure of being in the world. The fatigue remains the major issue of functioning in this world, but I am assured that this too will gradually abate.

## Comments

Wonderful news. A great milestone achievement and great to hear everything is on track.

xxx

*—Janeen Baxter, November 12, 2018*

A great day! Thank you for keeping us all apprised.

*—Ben Manski, November 12, 2018*

Sounds great! Love Peter

*—Peter Rosenthal, November 12, 2018*

Great news! Hopefully the food continues to taste good and the gradual exercise and crisp air bring you comfort.

*—Annabel Ipsen, November 12, 2018*

Ummmm .... WOW! Yes, doesn't really sum it up but what could? WOW!

*—Mary Jo Maynes, November 12, 2018*

So happy for this momentous occasion. And I hope you get to share a bed with no poles and tubes. What a joy for you both. Sweet dreams tonight!

*—Jody Whelden, November 12, 2018*

Very happy to hear that you have reached this important milestone. Stay positive and strong.  
Love to Marcia.

—*Lewis Leavitt, November 12, 2018*

Eriki and Marcia—I'm so thrilled for you to be at this new juncture in your health journey. Sending so much love.

—*Kathy Cole-Kelly, November 12, 2018*

I am so happy you enjoyed your dinner! I walked to see Ida today, but they were gone, so I left her my little present. It is an Italian overall, and I was afraid she would grow too much to wear it. Can we call you?

—*Magali Larson, November 12, 2018*

Fantastic news, dear Erik! So delighted that the meal tasted good - Sending you and Marcia big hugs and much, much love!!

—*Masoud Movahed, November 12, 2018*

Wonderful

—*Sarah Siskind, November 13, 2018*

Difficult to imagine a better turn of event, this so wonderful Dear Erik! Enjoy the freedom and fresh air. Marcia is amazing... peace and love to you both

—*Isabelle F., November 13, 2018*

Such wonderful news, Erik!! Much love to you and Marcia and the family xoxo

—*Madeleine Pape, November 13, 2018*

Ciao. I'm so glad!

—*Donatella Della Porta, November 13, 2018*

So glad to hear you're doing well and able to enjoy being out in the world and eating!!!

—*Becca Krantz, November 13, 2018*

Go Eric and Marcia! Enjoy Milwaukee.

—*Pauline Thome, November 13, 2018*

Hooray! This is so great. I've been waiting for this day. Enjoy the fresh air (and the turkey)! xoxo

—Tom Malleson, November 13, 2018

## Day 21: in our new apartment

November 13, 2018

It is about 10:30 at night. I think I have slept probably 20 hours out of the last 24. Marcia dragged me out of bed to take my night time meds and I seem to be slightly revived, so I'll write a blogette to keep everyone informed.

It turns out that we only had to stay at Kathy's House one night because the apartment in which we will be staying until January was cleaned and available. It is a sunny, small two bedroom place, perfectly nice for our needs, and very convenient to everything. The second bedroom will make a nice guest room for anyone who visits from out of Wisconsin. Tomorrow morning is my first outpatient clinic visit, so once we have done that our basic medical routine for the next phase of treatment will be in place. Let's hope the routine is uninterrupted by any exciting symptoms. I am so eager to be a boring patient.

## Comments

May the procedures go in the best possible way without any interruptions, dear Erik! Sending you and Marcia big hugs and much love! Good night -

—Masoud Movahed, November 13, 2018

Three cheers for boring! Glad you and Marcia have landed in a good spot for the interim. Hugs and peace.

—Margaret Vitullo, November 13, 2018

So happy you're in your new nest. Sending love. Xo

—Kathy Cole-Kelly, November 13, 2018

Sounds like a lovely little place. May you be a most boring patient! Sleep well!

—Sonia Baku, November 13, 2018



Boring is good! You did marry a good one. JJ and Betsy

—*John Posner, November 14, 2018*

I am so happy to read this this morning. Your steady recovery and fighting spirit are sources of both enjoyment and inspiration for us here.

Best wishes for you and Marcia

—*Mansoor moaddel, November 14, 2018*

## Day 22

*November 14, 2018*

### 1. Another story I composed in my sleep

I don't know why my dreams are so full of story writing, but once again last night I dreamt that I was writing a story. This time the character of the dream was a little different. When my children were little I often told them and their cousins stories, especially when we were driving or camping and the like. I never planned them out ahead of time, but they often revolved around a gimmick of some sort. I think of a story-gimmick as a story-generating machine: with a good gimmick in hand I would spin a yarn filled with silly happenings. Usually the kids were in the story as well, as in our endless search for the McMurtry chocolate mine in the Sierra Nevada. One of these stories was about two little kids named Josie and Jessica. The gimmick was that Josie could turn himself into any animal he wanted but he could stay that animal for only 30 minutes, and if he did this trick too many times in one day, then he would be stuck as the animal for 24 hours. This story-gimmick opened up a vast array of funny stories. Those were the stories I concocted 30 years ago.

Well, I guess it was time to have a new story-generating gimmick for my grandchildren, and in my dream this is what I concocted. The gimmick revolved around a typology of witches (who in the dream were both male and female) — and yes, in the dream this was built around a 2x2 table: (1) are their powers strong or weak; (2) do their powers work at a distance or only by touch. Then there were two other types, not in the basic set: (3) witches who could confer powers for a short time on nonwitches, but themselves had no powers. These witches were especially useful on construction sites where they could confer superhuman strength on a worker for a few hours. (4) Witches who were called “duos” who had a very wide range of powers, but those powers were only active when they were holding the hand of another duo. Most duos never learned that they are in fact duos, for they only become aware of their powers once in physical contact with another duo.

The opening scene of the story in my dream: Safira was visiting Vernon. Vernon was four years old; Safira five months older. Little Ida was one and a half. Vernon proclaims enthusiastically: “Wouldn't it be nice if we could fly?” “That would be fun,” Safira says and then hugs Vernon. Their hands touch and they rise from the floor.” And so the story begins.

Two other parts of the story-sketch. What to do with Ida? She needs to be part of this. This was my solution: Becky and Jenny soon learn that S&V have these powers. They go to the library to research the matter and find a very musty old book that talks about all of the different kinds of witches. In the chapter on duos, the book says that a person only becomes a duo on their fourth birthday. So, the big question is: does Ida have witch power? On Ida's fourth birthday Safira and Vernie hold hands, first just the two of them. They fly around the yard together. Then they land next to Ida, hold her hand and say "let's fly" and they shoot up into the sky like a rocket. They are the first Trio in the history of witches!

The other element in the story: I am the narrator of the story. I'm explaining various things about witch history and witch powers. I then say, "most witches are lovely people, trying to make life better for people. Sometimes they play tricks, but these are almost always playful. There are, however a few witches who do great harms. They are Evil Witches." Vernie then jumps up and yells, "No evil witches in my story." I explain that there are always bad guys in stories, that this is needed to give the story some conflict and tension. Vernon then says "My Daddy says that you don't need conflict in a story." [Adriano's most recent play, directed by Becky and still playing in Philly, is called "A Perfect Day." It is deliberately a story that is not built around conflict.]

So, there you have it. Once the kids are a little older -- four-ish I think -- I'll begin telling them the story of the three little witches and their adventures, with no evil witches.

## 2. Medical Update

I had my first outpatient clinic visit today, preceded by labs. The labs were super-annoying. I was scheduled for 10:20, but the lab had grossly overbooked appointments, so I wasn't seen until 11:05. Then the labs were drawn by a tech in training, so every step had to be checked by her supervisor. They had in their orders that my PICC line dressing needed to be changed, which was in fact an error since the nurse had changed it just before my discharge on Monday, which added another twenty minutes. And then they did not have in their orders that I needed blood drawn directly from my peripheral blood (rather than via the PICC line) to check the level of the anti-rejection drug in my blood. The tech-in-training first tried to get a blood draw from my left arm, but she couldn't get the blood to flow. She wiggled the needle around, trying to find a vein, but to no effect. So, her supervisor took over and took the blood from the back of my hand. She was also a little heavy handed -- no Etienne, alas.

Then I went to the clinic to see Dr. Hari, the head of my BMT team. Mostly excellent news: Hemoglobin jumped to 9.9, the highest it has been since March; 3,700 neutrophils per microliter; platelets only a little low. But also a slightly ominous number: 2% of my white cells were blasts. Blasts. The dreaded blasts. There are, however, two kinds of blasts: immature neutrophils that spilled out of the bone marrow because it's working in overdrive; and leukemia cells. It could be the case that these are all of the first kind of blast, but I suspect that they are the first reappearance of leukemia. We knew that the chemo and radiation I had in the run-up to the transplant was very unlikely to have obliterated completely my defective hematopoietic stems cells, so it was to be expected that we would have to contend with remnants producing leukemia. I suppose I had thought there would be a longer period before we had to contend with this, but as we say in cancerworld, it is what it is. I will have a bone marrow biopsy next Wednesday, which will definitively tell us what's going on. Dr. Hari said that we are in a very good position to fight this and that they have lots of options. The basic idea is to shift the levels of anti-rejection medications to allow the new neutrophils more room to maneuver in attacking these leukemia cells, to put me back on some oral chemo, and do some other things to strengthen the new donor cells. This is sobering, but I am not discouraged. And perhaps these will, in the end, be the happy blasts rather than the malign ones. No evil witches allowed!

## Comments

Definitely rooting for the blasts that truly are a blast! Sending love!!!

—Kathy Cole-Kelly, November 14, 2018

Tons of positive thoughts dear Erik. Yes, visualizing the non harmful blasts. We are rooting for them!!! Peace of mind and lots of love!

—Isabelle F., November 15, 2018

## Day 23 post-transplant

November 15, 2018



Four happenings of the day.

### **1. Visit by Barry Edlin, Pete Ramand and Kris Arsaellsson**

I had a wonderful visit from two of my current students, Pete and Kris, and Barry, now an assistant professor at McGill and a few years ago a post-doc in economic sociology at Wisconsin. Barry brought me a copy of his fantastic just published book, *Labour and the Class Idea in the United States and Canada* (Cambridge University Press, 2018). I recommend it to anyone interested in understanding the interplay between political institutions and the labor movement.

Their visit was wonderful. We had a free-wheeling discussion of theoretical and empirical issues in a paper I plan to write with Kris on the idea of direct citizen voting representation (the idea I discussed in the op-ed I wrote in October where there are multiple elected representatives from each district and, when voting in the legislature, each casts the number of votes they received in the election), and the themes of the seminar I hope to give in the spring (on the problem of emancipatory transformation: how to get from here to there). It was exciting for me to find the energy to be fully engaged in the discussion. This very much reinforced my feeling that if I am able, giving a seminar that would meet in my house would be a good idea for me, not just for students.

### **2. Marcia makes me a workstation**

Our little cozy apartment is pleasant, but there was no place for me to set up a proper workstation, so I had been using the kitchen table. So, Marcia went to Ikea, 20 minutes away, to find a small table. She returned and started to assemble the thing. It required a Philipps screwdriver to attach the brackets into which the legs would be screwed on the underside of the table. There was a Philipps in a drawer, but it was too small, so off to the hardware store went Marcia. The drill holes were a bit small, but with mighty effort by Marcia, two brackets were duly installed. Then Marcia discovered that she only had three brackets for four table legs. We looked everywhere, but the fourth bracket was nowhere to be found, so Marcia drove back to Ikea even though it was 7pm, got the missing bracket, came back and finished the job. Heroic effort. So now I have a nice place to work. (see photo below).

### **3. Taste buds are coming back**

It seems that my taste buds have decided to make life better for me. Today I had Marcia's wonderful scrambled eggs for breakfast, a ham sandwich for lunch, and a hot dog with sour kraut and baked beans for dinner. All were palatable. On the advice of one of the doctors, I brushed my tongue before meals, and maybe that helped, but in any case I no longer have to get my calories only from protein-fortified drinks!

### **4. Walk in the neighborhood**

Dr. Hari nixed the idea of my going to the gym any time soon. He said that I would have about a 30% chance of getting the flu if I went and if I got the flu, a 10% chance of dying. So that's out. So we tried a walk. The neighborhood is pleasant, with an elementary school nearby with a fantastic playground if my grandkids or grandnieces come to visit and even a set of adult outdoor elliptical trainer and rowing machines, which if it warms up a bit and I have more energy, I think I can use. (see photos below).



### Further thoughts on my 2% blasts

I try not to dwell on adverse numbers, but in this case this has been hard to do. The possible -- probable really -- reappearance of leukemia this soon after the transplant is scary to me. For so long I have focused on the transplant as the Big Goal, feeling somehow that once this was accomplished things would become straightforward. I knew this was not the case, but that is not how I felt. The thought that we already have to start battling the AML directly is discouraging and, as I said, scary. I will, of course, take things "one day at a time" (the oft-repeated cliché in cancerworld), and mostly that works. But not always.

One thing I will do is shift my attention a bit from my blog to my letter to my grandchildren, which I have neglected a bit in recent weeks. This was mostly because of exhaustion -- the blog takes less energy somehow to write -- but now that once again I feel the uncertainties about my future, it is time to make more progress on the letter.

### Photos





## Another story

*November 17, 2018*

For whatever reason, in this period of physical vulnerability and 16-18 hours of sleep a day, my mind seems to be playfully story-making. Last night I had another dream in which I wrote the framework for a story. This one, I think, would make a terrific movie. I think the seed for it was hearing the name Alan Arkin in connection with a radio discussion of his Netflix series, "The Kaminsky Method". Arkin wrote a fantastic book called *The Clearing* about a lemming named Bubber in search of spiritual enlightenment. I totally recommend this to everyone even though it is billed -- incorrectly in my view -- as a children's book. Kids will enjoy it, but it is definitely just as much a book for adults, at least adults like me.

Here's the set-up of the story, written in my dream:

A large group of forest animals is gathered in a clearing in the forest. They all speak perfect English and every one of them has memorized every line of every Shakespeare play. They would like to do a production on Broadway. "It would be a smash hit at least as a novelty," says a bear who likes to play hamlet. He can do it a la

Richard Burton or any other famous actor. "The problem," an owl says, "is that we need a human intermediary to arrange this." The owl flies off to find one and comes into my study where I am writing a story about animals gathered in a forest clearing who all have memorized the entire set of Shakespeare plays. It seems that when I write a story it actually becomes true, except that once the characters exist in the world and not just on paper they have a will of their own and are perfectly capable of doing things I hadn't written about. (Big theological implications here: God the creator but not controller....). I had not written anything about the owl going in search of a human producer. I then go to see my daughter Becky and her husband Adriano for advice on what to do, since they are both theater artists. Adriano makes some calls and then the three of us rent a big truck and head off to New York with the animals in the back. That's where the story writing breaks off.

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No real medical update today. My next outpatient clinic appointment is Monday when I will have more information. Mostly I am very tired and sleeping much of the day. I rouse myself to take medicines, eat, and see visitors -- which I especially enjoy. But then I crash and sleep.

## Comments

Sending you and Marcia big hugs and much, much love -

—*Masoud Movahed, November 17, 2018*

I love this plot line! For some reason it evokes memories of Blyton's "Up the faraway tree", which I grew up on (differing political proclivities of the authors notwithstanding!) Did you ever read that? Something about the magic and the whimsy feels familiar. xoxo

—*Tom Malleson, November 17, 2018*

This made me think of Grimms' fairy tale about the musicians of Bremen. Much love to you and Marcia from Janeen and me.

—*Mark Western, November 17, 2018*

This would be a great story. Since someone mentioned "The Musicians of Bremen" I wanted to send a photo of a tiny statue of them that one of my students gave me. But I don't know how to post an image - guess I'll have to send it to you.

—*Mary Jo Maynes, November 19, 2018*



## It is what it is

*November 19, 2018*

I had a blood draw and clinic visit with the head of the transplant team today. The news was mostly "bad news" -- let's reframe that as "unfortunate news" or "not what we hoped for." The blasts that made their appearance in last Wednesday's lab results increased from 2% of my white cells to 8%. This means that they are leukemia cells. It is not unexpected that eventually the AML would manifest itself, but the hope was that this would be after my new immune system was fully established -- more like 100 days post transplant rather than 23. Dr. Hari said that there were things that they can do and that I still have "some chance" that everything would work out. "Some chance", taken literally, means a chance above zero, but I didn't ask him for clarification. The strategy will be to first, do a bone marrow biopsy on Wednesday to get a more fine-grained picture of what the AML is up to in my bone marrow, and then next week, stop the anti-rejection medications (I think he said "stop" rather than "reduce") so that my new immune system will feel freer to attack my old immune system. This will be combined with some new chemo which they hope will affect the AML stem cells and blasts more rapidly than my healthy new immune system. As you can see, this is complicated involving quite delicate calibrations of contradictory imperatives -- this is all very dialectical -- and there are no certainties at all as to how well this will work.

I remain hopeful, to be sure, but it is hard to sustain a robust sense of optimism in light of these developments. This is kind of like my real utopias vision of overcoming capitalism: the idea of real utopias is meant to kindle hope, a belief that there is some chance this can happen, but it doesn't make the optimistic prediction that in fact the strategy will succeed. Hope and optimism are close cousins, but not the same. I do remain hopeful; there is a real chance (I like real over some) things will work out. That's the way things are. It is what it is.

## Comments

Oh boy. You are beautiful. And you are correct. There's always reason for optimism, I am sure too.

*—Sarah Siskind, November 19, 2018*

This Is indeed not what we were hoping for. We remain fully on the side of hope though, and fully support the dialectics involved. Sending tons of good vibes and love, and peace of mind too.

*—Isabelle F., November 19, 2018*

Erik, thank you for keeping us up to date. You are very much in my thoughts. Joining you in hope and optimism. --Adam

*—Adam Gamoran, November 19, 2018*

I'll try to think of this as merely unfortunate news, but I don't know how you can write in such a measured and

sensible way. It sounds as if you've got great docs; and they have the greatest patient. Surely, that's some ground for hope.

—*Dan Hausman, November 19, 2018*

Erik, your positive attitude has gotten you this far, and I have faith that it will take you all the way. Hang in there, let yourself recalibrate, and tomorrow will be better. Sending you “lift-your-spirit” vibes.

—*Rachel Schurman, November 19, 2018*

thanks for the update, and sorry it is what it is now. But real optimism is warranted still, especially as your docs seem to be very good at the dialectics of your body. Spirit and hope are not everything of course, but they will surely play a role too in keeping your system doing all it can - maybe a meditation on the tightrope walking the doctors are asking your immune system to manage? Sending all good vibes for you, Marcia and your whole medical team.

—*Myra Ferree, November 19, 2018*

Dear Erik: Hang in there. I am quite optimistic and the chance is in fact real that you will overcome this hurdle. With lots of love for you and Marcia.

—*Mansoor moaddel, November 19, 2018*

Thank you, Erik, for sharing with us. You and Marcia continue to amaze me, in the most positive and beautiful ways.

With love and continued admiration and optimism, Julia

—*Julia Adams, November 19, 2018*

Yes! As everyone is saying, we wanted different news, but we know that you still have a lot of stories to tell and to live and you will persist!

—*Mary Jo Maynes, November 19, 2018*

Betsy and I are of course disappointed We do hope that the course of your AML can be reversed JJ

—*John Posner, November 19, 2018*

thanks for the update, Erik. While I'm sorry with this new development, I remain very much hopeful and optimistic. Hang in there.

—*Chaeyoon Lim, November 19, 2018*

I remain hopeful as well, Erik.

—*John Gastil, November 19, 2018*

Erik, you have been amazing through all of this, and your combination of resilience and realism is inspiring. .  
Sending so much love....

—*Gay Seidman, November 19, 2018*

Sandy and I send much love, along with admiration. We are with you. A huge hug - Jenny

—*jane mansbridge, November 19, 2018*

Erik-- You are an amazing human being and hope is a very positive force. Sending love to you and Marcia

—*jeannette golden, November 19, 2018*

Erik - sending you and Marcia heaps of love, optimism and hope. Hang in there and stay positive.  
xxx

—*Janeen Baxter, November 20, 2018*

@#&%!

I appreciate the distinction between hope and robust optimism. Thanks for being such an amazing teacher, even in the face of this news. And I love the stories from your dreams. Some of my most interesting and easy-to-write scenes come from my dreams, when I can remember them.

—*Becca Krantz, November 20, 2018*

Erik te mando un gran abrazo y mucha fuerza.

—*Rodolfo Elbert, November 20, 2018*

Thinking so so so much about you guys Eriki.....I'm going to be keeping all fingers and toes crossed that your own immune system can go on full frontal attack. Sending you so much love! Kathy

—*Kathy Cole-Kelly, November 20, 2018*

Xo

—*Heather Crowley, November 20, 2018*

I'm very sorry to hear the latest, but I'm also heartened to read your map of the road to recovery. Your spirit shines through. Wishing you and yours all the best. And I'm very much looking forward to reading more of your letter to your grandchildren.

—*Adaner Usmani, November 20, 2018*

Erik and Marcia : we are heartened by your resolve and hope. We are entering the season of miracles a time when the new cells of the transplant are finding new life in their new home. We have hope too that they might prevail over the EvI (I) ones! We know it's a hard time for both of you. We send you love, and hugs.

—*Lewis Leavitt, November 20, 2018*

I know it is a very difficult time for you and Marcia - sending you all the love I have, dear Erik. I learned from you to remain hopeful in the face of challenges. My heart and mind are with you! Much love -

—*Masoud Movahed, November 20, 2018*

Erik and Marcia

We are in awe of your unwavering strength and courage. With all love and good wishes. Peter, Carol and the Toronto crew.

—*carol kitai, November 21, 2018*

Hi Erik, Ulpi and I are thinking of you and Marcia, and sending our love to you both. We remain hopeful and optimistic. Abrazo

—*Cesar Rodriguez Garavito, November 22, 2018*

## medical update & Happy Thanksgiving

*November 22, 2018*

Happy Thanksgiving everyone. I feel I have much to be thankful for in spite of everything: I'm alive; my fantastic donor of stem cells, who is trying to keep me that way; Marcia, who has made this intolerable ordeal tolerable and often a pleasure and is working so hard; the medical team which is doing their damndest to get me though this disease; and all of you whose expressions of love have deeply bolstered my spirits. And now let me rant: *I really HATE acute myeloid Leukemia. It should be illegal. A malevolent disease that continually wrecks havoc. I'm fed up with being exhausted and lately a bit queasy all the time. I love being alive and*

*desperately want to stay this way for a couple of decades. It would be so stupid to die now; to imagine not being part of the lives of my wonderful grand children makes me unbearably sad. As Marcia has put it, this reality is so unreal.* Enough ranting. As my extraordinary grandmother, Sonia Posner, would say, "it doesn't pay." [She made this comment when she was about 80 and totally blind and was talking about why she would never consider suicide.] I am alive now, damn it!

### medical update

Yesterday I went for another bone marrow biopsy, only this time the provider said that she used an electric drill to get into the marrow rather than the hand-auger that had been used in my previous six biopsies. She said she preferred it because it was much quicker. I had perfected my meditation routine around the hand auger, so initially I felt some anxiety about the change. An electric drill sounded pretty grim. So, I focused my meditation, told my pain receptors to remain relaxed as Janet had instructed me, and away we went. It was indeed quick -- I think only about a minute. And it wasn't painful -- my pain receptors followed my instructions. My usual visualization of walking through a jungle between high hedges, however, got a bit scrambled because the PA doing the biopsy said "we're done" while I was still in the middle of the path. When she said "we're done" the hedges just sort of melted away.

The next phase of treatment will be clarified by the biopsy. I'll have the results on Monday. What is already clear is that the AML is energetically back. In the latest lab numbers, from yesterday, the blasts hadn't changed (actually dropped from 8% to 7%) but my platelets had dropped quite a bit, which is another AML symptom, and my hemoglobin had dropped a bit. Once again, I experience this in terms of a military metaphor: my new stem cells were still in training when the enemy attacked. Another month or so they would have been ready, but now they have to fight without fully being prepared for the battle. The bone marrow transplant team will do their best to bolster the strength of the donor stem cells and weaken the AML, but it is a daunting task.

## Comments

I'm rooting hard as I can for the new team!

—Gay Seidman, November 22, 2018

I'm feeling your anger at the AML and praying for your new stem cells or other treatment to push it back. You have given so much to all of us and we quite selfishly want to keep you around as long as can. You can know that you have a whole world of people who care about you and are rooting for you.

—Pamela Oliver, November 22, 2018

With any luck, this too will be overcome. Happy thanksgiving to you, to Marcia, and to your entire "family."

—Mark Gould, November 22, 2018

I am thankful that we have you as a friend. Love, Jenny

—*jane mansbridge, November 22, 2018*

I'm writing from Brooklyn, where we are with Liz for the weekend. We all send love and hugs to you and Marcia. We agree that AML has got to go ... Yours and everyone's!

—*Mary Jo Maynes, November 22, 2018*

I am super thankful too, and focusing on seeing the new cells surging in full strength mode to Victoriously fight back the AML. But it is what it is, as you say, and hope you have a wonderful celebration today. We are all rooting for you. Love and peace of mind to you and Marcia and your entire family.

—*Isabelle F., November 22, 2018*

erik, it is so painful to read about this setback but i hope you realize how brilliant your blog has been, how insightful, funny, ironic, dramatic, and a lesson in maturity. Moving and inspiring

—*Jeff Alexander, November 22, 2018*

I hate the AML too! Bad, bad actor. But I'm hoping the donor stem cell trainees will gird themselves for battle and with a rallying cry from all of us that care about you--bring an end to this!

—*Sonia Baku, November 22, 2018*

Eriki & Marcia: I am so grateful today and every day to be able to call you my friends. To know you is a gift in my life. I love you both.

—*Jennifer Wilgocki, November 22, 2018*

Erik, I too am sorry to hear that the AML is rearing its head now. Alas.

I am working on a metaphor related to the mid-terms. Let's see. The first news didn't seem as promising as we hoped. Then it got better and better. ("It's not a blue wave", "it *is* a blue wave", "it's not", "well, actually it is .. bit by bit...") I hope the same for your team - i.e., that it will reveal its good news incrementally. In the end, the House is alive and in our hands (arms) -- as you shall be (i.e., alive and in the arms of your loved ones).

xxx Janet

—*Janet Gornick, November 23, 2018*

We are pulling for you ... think of you daily. who knows--anger may be strengthening, to continue the military metaphor. Linda and Allen

—Linda Gordon, November 23, 2018

## very brief update

November 23, 2018

The labs and clinic appointment today confirmed the unfortunate news of my last report: the blasts increased quite dramatically since Wednesday, from 7% of white cells to 22%. Dr. Hari felt that this was of sufficient concern that he started one of the chemo drugs -- hydroxyurea -- today rather than waiting until next week. This is what I was taking in August and September and again in the run-up to the transplant. It was quite effective in reducing the blasts. Monday we will have the full report of the biopsy and a strategy discussion with Dr. Hari. I anticipate that the priority will be to push back the AML as quickly as possible and then worry more about securing the transplant's health, but we'll see.

Yesterday, Thanksgiving Day, I was also beginning to have some pain in my spleen, which is also a sign of resurgent AML. I called the clinic and the nurse on call called Dr. Hari who prescribed a small dose of a steroid, dexamethasone, to reduce inflammation. I will only be on this for a few days, but it gave me a huge burst of energy today. That was a good thing, because this afternoon Jenny, Mark and my super energetic three-and-a-half year-old grandchild Safira came for a wonderful visit in the afternoon. I had enough steroid-supported bounce to spend a good deal of time at the playground near our apartment and then later in the afternoon fiddling a kind of wild deconstruction of a Virginia Reel for Safira. It involved lots of chasing and circle-swinging by the wrists, but hidden in the melee were a few Virginia Reel moves. It was a joy to be with them. They are gone now and I am not even exhausted. It is too bad even small doses of dex have significant side-effects if used for more than a few days.

## Comments

Your perseverance in the face of such challenges is so inspiring, dear Erik! Sending you and Marcia (and the entire family) lots of love.

—Masoud Movahed, November 23, 2018

Oh, my. I am so glad you got to play outside with Safira today, so glad you are surrounded by family and friends. And that you have access to amazing health care. Sending so much love.

—Gay Seidman, November 23, 2018



I'm sending my best wishes for a Stamp Out of AML!

—Debra Satz, November 23, 2018

Glad you had the energy for some enjoyable kid time, especially on a weekend with so much discouragement. Wishing you many more such family days!

—Myra Ferree, November 23, 2018

## scientific correction

November 24, 2018

I think I got the story of the battle between my new and old immune systems wrong. It is not the neutrophils that charge into this battle. They only know how to attack bacteria, which is why being neutropenic makes one vulnerable to infections. The component of my new immune system that needs to be ramped up to deal with my AML are the T-cells, and they are much slower to develop than the neutrophils. So that's the problem with this early reappearance of my refractory AML: my T-cells are not up to the task yet. That would take something around 100 days post-transplant. I'll confirm this on Monday when I see Dr. Hari and see what the new treatment plan is.

I will write a longer blog tomorrow. Right now I want to get back to the letter to my grandkids.

## Comments

Looking forward to reading more of the letters you have been writing for them. Sending you and Marcia big hugs and much love!

—Masoud Movahed, November 24, 2018

Thinking of you, Erik.

—Paul Dudenhefer, November 26, 2018

## Real Time Report from the Field

*November 26, 2018*



### **2:30 p.m., November 26, Froedtert Hospital.**

I'm sitting in a classic chemo chair in a nice, airy, chemo infusion cubicle. It's quiet, no commotion. I'm waiting for the first infusion of my new treatment plan, decitabine.

### **2:45 p.m.**

Decitabine is now dripping for the next hour. I'm surrounded by snacks. Marcia went down to the business office to deal with our first insurance glitch since this all began — not bad, one glitch in nearly 8 months!

The new treatment plan is all set. Here is the situation: I confirmed with Dr. Hari that all of the action concerns my new T-cells. These are the cells that are vital for the fight against the remaining mutant hematopoietic stems cells that produce my acute myeloid Leukemia. Neutrophils have nothing to do with this.

So, I need to adjust my metaphors to carry on the drama. No more rugby. T-cells are the warriors in the battle ahead; T-cells definitely do not play rugby. I can't seem to avoid it, but I think the military metaphor is going to have to drive the narrative. T-cells are special forces, green berets, navy seals, take your pick. They take a lot of recruitment and training. Neutrophils are a dime a dozen. They develop quickly and then are out doing their business and playing rugby, and then within 24 hours they're dead (Dr. Hari said it was 24 hours, not 5). T-cells are more serious. Hard working, hard training, no monkey business. They survive for months in the peripheral blood. Dr. Hari, who has studied T-cell boot camp, says that with freshly transplanted stem cells it takes 1-3

months to get a full up-to-strength set of T-cells. Tomorrow it will be five weeks since my transplant, so the T-cells are definitely still in training, not up to their best. I know they're working hard, but there is only so much they can do.

While they are developing we have a more pressing immediate task: My AML is back in force, nasty, aggressive, high levels of blasts, already doing some nasty work in my spleen (moderate pain indicates this). So, the first order of business is to Smash the Blasts, and that is what my chemo is designed to do. This week, five days of IV-infusions of decitabine. Hari wanted to add a newly available oral chemo to this, but the insurance rejected it because it hasn't been approved by the FDA, so that is being appealed. He is certain the appeal will be accepted. Don't worry, he told me. That will be added by the end of the week or next week. Hopefully these drugs will knock down the blasts in the peripheral blood to a low level. If not, there are other options in the wings.

Once the blasts level are down, then the fight really begins. Here the central theme will be that to unleash the new T-cell special forces against the resurgent AML requires reducing the anti-rejection medications so that the new T-cells feel they are in a more alien environment. This will trigger some level of GVHD [Graft versus Host Disease]. This will produce nasty symptoms. The most common are fever, rigors, rashes, and diarrhea. Hari said he looked forward to seeing the symptoms since I needed some level of GVHD in order for the strategy to work. He said that they had good medications to counter these side effects. I asked him whether it mattered which symptoms appeared. He said no, a version of any of the symptoms would be fine. That got me thinking: do I have a preference ranking? I hated the fever spikes and rigors I had earlier in my treatments. And the rashes from GVHD are described as "volcanic" which sounds pretty nasty. Rashes itch. I hate itch. So I picked diarrhea, which at least cleans out your system, and unless severe can be managed pretty well. I asked, "Should I celebrate the diarrhea when it comes?" He laughed. I'll celebrate.

If all this gets scrambled and doesn't work, there are more options.....(*Done with infusion. To be continued when I get home*).

#### **4:15, back at our cozy apartment, 3 minutes from the hospital.**

Dr. Hari has lots of other options ahead if this doesn't work out successfully. "We have lots of options, lots of clinical trials to tap into." He drew a diagram of options (see below). We hope to be following the most right-hand stream here. When my clinic visit was over, he parted by saying, "I never give up." I replied, "Me too, I never give up."

#### **5:30 p.m.**

Two things before signing off for today.

First, I have been on a mild dose of dexamethasone, a lovely steroid for my spleen pain, since Friday. It has given me terrific energy and focus, and virtually no fatigue. The feeling is amazing -- tasting my future, I hope. But alas, Dr. Hari told me today that I would have to stop it after the morning Dex tomorrow, so by Wednesday it will be pretty much out of my system. "Can't I occasionally use Dex for some respite from exhaustion?" "No," he replied instantly, "never use steroids just to get energy." So I won't. I follow instructions.

Second, I had a brief conversation with the T-cell special forces recruits in the central bone marrow command center, somewhere in my left pelvis. The scene was a bit tense -- the remnant stem cells from my old system producing AML were also in the pelvis doing their malevolence, so there was often confusion and a bit of chaos. But the T-cells were undaunted, filled with energy and ambitions. I spoke to one.

"What's your name?" I asked.

"Don't have a name, Sir. Just call me T-cell 1376528."

"OK T-cell 1376528. What's the situation here? How are things going?"

"Pretty bad at the moment. We can't quite figure out what's going on. There are all these cells in here buzzing around that aren't descendants of our hematopoietic stem cells, but they also don't seem like alien intruders either. They're a bit off -- kind of rude, pushing us around, no discipline, messy. But they also seem sort like one of us so we are hesitant to do anything about them. Still, we're training hard and new recruits are showing up pretty rapidly. We'll be prepared to take on any enemies soon, soon, soon. I'm sure."

"That's good my friend, T-cell 1376528. Those annoying cells are called blasts. You tell your comrades that I have enlisted the help of a fantastic team to try to get rid of most of these annoying cells. We're poisoning them. I hope the poison doesn't affect you, but we have to destroy the blasts so you can train and develop. You're right that they are not your cousins, but don't worry about that. Just keep up the training and grow strong."

"Not to worry. We are all very serious. No rugby."

## Photos



## Comments

You, your family, and your doctor make a great team, Prof. Wright! Wish you all the best of luck in your fight against the blasts and insurance companies!

—*Kerem Morgul, November 26, 2018*

Sending much love!

—*Gay Seidman, November 26, 2018*

Every battle requires relief distractions. I offer 3 from my day on Morrison St, Madison -1) cold but dry. 2)I watched CBS AM news & Bernie was on, sounding like a candidate. 3) Made & ordered my holiday card. Will send one to you guys.:)Warmly, Jody

—*Jody Whelden, November 26, 2018*

Big-ups to Dr. Hari who laid out the plan of action and figured out the various options we have at our disposal!!Sending you and Marcia big hugs and lots of love!!

—*Masoud Movahed, November 26, 2018*

Erik I'm sure your internal team will do MUCH better than the Badgers and the Packers did against MN this week :)  
See you soon.

—*Jonathan Patz, November 26, 2018*

You rock!!!! Your resolve and patience are wonderful and we are all believing in you and dr Hari s expert leadership. Rooting for your fantastic team!!!!

—*Isabelle F., November 27, 2018*

T-cell 1376528 sounds like a really dependable guy....

—*Hillel Steiner, November 27, 2018*

Erik, I happily salute your T-cells! Onward into the breach!

—*Nancy Folbre, November 27, 2018*

Mesmerising story, Erik, hope you will continue writing thrillers after you have defeated AML.

—*Lennart Olsson, November 27, 2018*

## Delayed blog — not to worry

*November 29, 2018*

It has been. Few days since last I wrote, and a couple of people have expressed concerns over my situation. It has been a rough couple of day — details to follow — but nothing of grave concern. If it should come to pass someday that something really serious happens, I'll get Marcia to write the blog, so don't worry if I skip a couple of days here and there.

Here's the story: I stopped taking magical dexamethasone Tuesday morning, but I was still left with enough energy to actually finish Part I of my Letter to my grandchildren, 45,000 meanderings words through the 1950s. I was planning to write the blog for that day Tuesday night, but at 7pm it was as if someone unplugged me, turned off the master switch. I was totally whacked. I had been sitting with Marcia at the kitchen table and my head suddenly felt it weighed like a watermelon, so I put my head on the table nestled on my crossed arms. No way could I write anything. Went to bed, terribly restless night.

On Wednesday morning I had standard labs and then a clinic visit. My Spleen pain was getting worse, especially when I coughed. When I went in for my clinic appointment the first thing that they do is "vitals": blood pressure, pulse, oxygenation and temperature. When we got to the temperature part of the agenda it was 101 and change. Twenty minutes later it was 102.9. Dr. Michaels is felt I had to be admitted to the hospital, first to the ER and then eventually when a bed became available, to the hospital proper. We were taken by transporter to a perfectly comfortable ER cubicle, and then to a private ER room, and finally at 10 pm to the hospital proper. There were five hemonc rooms available, one on CFAC and 4 in a regular hospital ward. To my great relief, we got the CFAC room.

Then last night things went from bad to worse. The spleen pain was terrible, the fever remain high (although they let me take Tylenol to knock it down a bit) and I was so weak in bed that couldn't turn over, sit up or even scooch around in the bed to get comfortable. Extreme temporary weakness is apparently sometimes a symptom of leukemia fevers. At 2:00 a.m. the PA on the floor finally invited me to take a low dose oxycodone. I'm very wary of any narcotics because of their constipating effects, but I gave in to get some rest. By 4:00 I was sleeping fitfully.

Today is better. The spleen pain is still there, but not quite as intense. The fever is down, and mostly the severe weakness is gone. Soon I will be having a CAT-Scan of my spleen to confirm what is going on and then I will be started on some medications to deal directly with that. I've also decided to go ahead with some modest narcotics for the pain. The PA convinced me that it will be only for a few days and, she announced, "I'm the poop queen. We'll come out with guns blazing with things to counter the constipation." Since this is really only for a few days, I guess I'll go along with her advice.

As things look now, I should be in the hospital for another 4-5 days or so. They need to figure out the fever before they resume the chemo to fight the resurgent AML and then be sure everything is stable.

When I woke up I told Marcia about a very strange dream snippet I had: I dreamed that our house was overrun with zucchini's — piled on shelves and on tables, lining the countertops in the kitchen. Marcia said, astutely, "The mind is a strange thing. I think that the zucchinis were leukemia."

## Comments

Erik- You are being tested with so many challenging situations. Again I so wish I had a magic wand, but I also know from having gotten to know you much better through this time, that if anyone's spirit will rise to all those challenges it is yours. Sending so much love to you and Marcia.

—jeannette golden, November 29, 2018

I am very sorry to hear that the last few days were so rough - Sending you and Marcia big hugs with all the love I have!

—Masoud Movahed, November 29, 2018

Damn those zucchinis! Oh how I and all those who love you and Marcia wish this was easier. It sounds like you, Marcia, and those wonderful health care practitioners are on the case! Hoping the next days are much easier.

Love,  
Sonia

—Sonia Baku, November 29, 2018

Thanks for these updates - we were wondering what's been going on. Hard stuff, but the end of the entry - about the zucchinis - is precious. I'm sure Marcia's interpretation is on the mark ... What's the medical equivalent of using all those late-season zucchinis to make ratatouille?

—Mary Jo Maynes, November 29, 2018

Marcia is indeed astute. And you've got a lot of folks working hard to get rid of those zucchinis,

—Myra Ferree, November 29, 2018

Much, much, much, much love!!!! from Sandy and me

—jane mansbridge, November 29, 2018



Sounds like a rough period. So glad you have your steady and insightful co-pilot by your side. Sending so much love. Xoxoxo

—Kathy Cole-Kelly, November 29, 2018

Dear Erik. I am so sorry to hear it's been so tough. I am thinking a lot about you and Marcia at the moment. There is no comparison, but I've been on oxycodone and codeine for the last 2 weeks, which is what you get when you're foolish enough to break a bunch of vertebrae. The constipation can be managed. Love to both of you. Mark.

—Mark Western, November 29, 2018

Dear Eriki, I am sorry that this journey has so many perilous twists and turns. You and Marcia are showing us the incredible art of going day by day with hope. I am imagining those zucchini piles quickly composting to make fertile soil for whatever is growing next in your garden. Love, Amelie

—Amelie Davidson, November 30, 2018

## More Reflections at being “at home” in my body

November 30, 2018

The past few days have been an intense encounter between “me” and “my body.” I don’t know if this is exactly the same as the well-worn “mind-body” problem. Perhaps it is. But my experience is not exactly about my *mind* but about something more encompassing: “me”. My thoughts here are not especially coherent; more of a jumble. But I thought I would write them down anyway.

I was so uncomfortable with my body for the twenty four hours when things were at their worst that it no longer seemed *my* body — I didn’t fit. It was like when you have a canvass cover for an outdoor grill and no matter what you do you can't get the contrours of the grill and the cover to align. I wasn’t nauseous and I didn’t have a headache, but my spleen pain was pretty acute, I was extremely weak and uncomfortable all over. I don’t know how better to describe it. Then yesterday the doctor convinced me to take dilaudid, a very fast-acting, short-lived IV pain drug. When it is administered to the IV, I instantly feel much better, but it only last an hour, then equally abruptly its gone. The short-acting quality is I supposed disadvantage but it makes me feel in control, and suddenly I felt at home in my body. We were reunited. At home and at ease.

I will continue this for a few days until my spleen enlargement has decinlined to the point where it not longer hurts. According to the CT-Scan, it is currently about 50% enlarged. The main strategy to reduce it is to get my white cell count down, which is central to fighting the AML anyway. All of this will delay for a week or two the full strategy for dealing with this phase of my illness. Basically we are sort of back where I was in April, except

with a new immune system coexisting with my mutant hematopoietic stem cells. The immediate task is to regain whatever control is possible over the Aggressive AML. This is why D. Michaelis is back in action alongside Dr. Hari — the heads of the hemonc BMT teams.

## A very disturbing, bleak moment

*December 2, 2018*

I was hesitant to write about this incident because it is so hard to put it into words and it was so powerfully disturbing. I was sleeping yesterday afternoon and had an extremely brief dream snippet, not a full-blown dream with a narrative structure. The whole thing probably lasted a second or less. It was a malevolent scene, not a story: I opened a door to a room that was filled with everyone I love and who loves me -- all my immediate family, grandchildren, extended family, friends, students, colleagues. Everyone. And they were all laughing at me, mocking my efforts to understand my illness in my blog, saying I was ridiculous. There were no words but there was an instantaneous conveyance of meaning. I let out a scream and woke up sobbing, gasping. This, I feel, was the worst nightmare possible -- the very foundation of my life, love, became empty. I have firmer beliefs in the love I experience in the world than in my critique of capitalism. If love is false, there is nothing, nothing. I know what the dream expressed is not true; there is not even a shadow of doubt in my certainty about my feelings. But this flash of self-denunciation

### **Later.**

When I wrote the last partial sentence, I burst out into loud uncontrollable sobbing. It took 15 minutes or so for me to regain control. I then meditated for half an hour, at Marcia's suggestion, and this dissipated the emotional turmoil.

I want to wrap up this blog with a few reflections.

I'm not sure what I was going to say after "self-denunciation", and it doesn't matter. This was the first time since the dream -- 24 hours of talking to Marcia and reflecting on it -- that this expression popped up, and it was the word that triggered my emotional melt down. It certainly reflects the way the dream was an attack on my confidence that I was the person I thought I was.

How to explain this? Why now? This has been an emotionally draining period and, of course, a few days ago I was physically miserable as well. Taken together this certainly made me vulnerable. But there are two other things. The pain med I am taking -- dilaudid -- lists as one of its "rare" side effects "abnormal dreams." This may be in play. But there is another, interesting, subconscious force screwing around with my symbolic universe: THE GOOD PLACE.

Marcia and I have been streaming *The Good Place* on Netflix. It's quite interesting if you have the patience to watch sufficient episodes to see how they build on each other in interesting, complex, layered ways. Individual episodes can come off mainly as silly. One of the many quirky aspects of the show is that nearly every episode includes a short, often interesting, mini-philosophy lecture on ethics. I especially liked the exposition of the "Trolley Problem" in an episode in season two. The "Good Place" is supposedly "Heaven"; the Bad Place, hell. Dead people go to one or other (mostly). At one point in the series, an official in the Bad Place

is trying out a new way to torture people for eternity by designing each person's worst emotional nightmare. We had recently watched an episode in which this task was laid out. Well, if a Demon of the Underworld or Hell wanted to torture me for eternity, making me feel that the dream I had yesterday was Reality would be the way to do it. Perhaps the idea of The Good Place was buzzing around in my head and intersected my vulnerabilities, emotional exhaustion and the interactions of all the drugs I have taken.

\*

I always try to see if I've learned anything from terrible experiences. Perhaps this experience is something like the mental experience of a psychotic break -- the paranoid feeling that everything you thought about other people is false, that everyone is out to get you. If this had pushed me over some tipping point where I came to believe that this horrible thought was true, that would make me crazy. The rapid breathing, gasping for air which I experienced in the emotional turmoil of the aftermath of the dream and my writing about the dream may be something like a panic attack. The most important thing, perhaps, is ironic: the horror and falseness of the dream's content revealed to me as nothing else could the centrality of love to meaning, for me anyway. I don't think a year ago I could have written the sentences above, "I have firmer beliefs in the love I experience in the world than in my critique of capitalism. If love is false, there is nothing, nothing." If someone had asked me if I agree with it, perhaps I would have said yes, but I would not have spontaneously said it.

\*

One final thing: This is just a description of my experience. It has not shaken my beliefs in the web of love in which I live one bit. It is not a plea for reassurances.

## Comments

Erik, you write about this experience so openly and profoundly ... the web of love in which you exist and help weave is always there, always visible, through what you write and in people's responses -- even just here on this blog. So I understand the 'no reassurances necessary'. Still, I can understand why such a dream would be the very thing that would be most frightening. To many (most?) of us, it's our deepest fear.

The other day, I was telling one of my sisters, who is developmentally disabled, that she shouldn't watch so many disturbing TV shows, or at least that she should leaven them with something more cheerful. She considered for a bit but then rejected my advice. I can only assume, from her and now you, that these shows must be great. But I'm going to switch on the Hallmark Movie myself!

With love and admiration for you and Marcia,  
Julia

—Julia Adams, December 2, 2018

I will also refrain from reassurance since you don't need or want that as a response, Erik. But, like Julia, the horror of the dream really did hit home from your description. You don't want reassurance from us, but I appreciated being reassured by your explanation of the genesis of the nightmare. That made sense to me and was a better account than some others might have been. I just had a conversation last night with some former

students who were telling me how amazing "Good Place" is. I have been resistant. Sounds as if you and Marcia have really been enjoying watching it, but then !! ??

—Mary Jo Maynes, December 2, 2018

Ok, I know you don't want reassurance, but I can't help myself: Eriki, you are so deeply loved! And always will be.

Gay

—Gay Seidman, December 2, 2018

Erik, we have all (re)discovered through your sharing how much we respect and value you, how much we think of you and Marcia within our circles of loved ones, how much we are all on our side. Special, I think, has been the opportunity to watch an intelligent and mature person grow and develop; we are privileged to share in your experiences, in your pains and sorrows, and in your joy. We all hope, and no doubt some of us pray, for your recovery, selfishly, because we all want to continue to benefit from your reflections, and from your generosity and caring.

—Mark Gould, December 2, 2018

This is not reassurance; it is just what my heart screams: DREAM, YOU LIE!!!! Waking Eric, you are right. The love everyone feels for you is palpable, and makes us better people as well. Thank you for all you honesty and emotional/intellectual penetration. This is what the world is for. Love, Jenny

—jane mansbridge, December 2, 2018

It is really hard to read this without bursting into tears for anyone who has ever interacted with you, dear Erik. You cannot imagine how much we miss your beautiful smile in the department; your open and gracious arms to offer unstinting moral and intellectual support of all sorts. I could never imagine that I would develop such strong emotional ties with my mentor and adviser. To say that I love you is an understatement of how I (and my peers) feel about you. Thinking of you every day, every hour. Sending bigs hugs to you and Marcia!

—Masoud Movahed, December 2, 2018

Also, I thought it would be good to share a euphoric piece of classical music. Much love!

<https://www.youtube.com/watch?v=bs-tyF95MYA>

—Masoud Movahed, December 2, 2018

As a student (and in the name of all): Erik, we do love you and admire you!

—Rodolfo Elbert, December 2, 2018

hardly surprising that you'd have such a nightmare--you're living through something traumatic to say the least. But if it would be reassuring, try to count (mentally) all those who care about it--you would be counting all day and all night.

meanwhile, for a good and charming distraction, watch/listen to this rendition of the internationale by Chinese pop singers:

<https://www.youtube.com/watch?v=PZID5RXkeuA>

—Linda Gordon, December 2, 2018

Out hearts go out to you and Marcia.

Martin and Mona

—Martin Goldstein, December 2, 2018

Erik- I respect your statement that you are not asking for reassurance, Just reading all the comments on your blog over time is proof of the love that surrounds you. I will say that your description of the dream was so deeply sad, and once again your ability to connect to others through sheer emotional honesty is a life lesson for me. Sending love to you and Marcia...

—jeannette golden, December 2, 2018

Oh, Eric, as a person who dreams vividly, and rarely happily, almost every night, I can relate to the horror of torment from a nightmare, even a snippet of one. When one is ill, I think it is easier for what might be called primal fears to surface in dreams. Hoping this was a one-time episode, and that you can sleep untroubled tonight. Hugs from Eve and John.

—Eve Silberman, December 2, 2018

Erik, reassurances are not the point of saying that you are loved — and evoke such love because you give it - it is a matter of empirical fact that we all insist upon. I trust that when the drugs and bad TV have done their worst to frighten you, your wakings will be steadily refilled with love from near and far, because there is a great supply of it available for you. I found your saying you believe in this web of love even more than in your critique of capitalism to be profound as well as profoundly moving. I recognize in that the energy that moves you to try to create a better world and thus as the most fundamental source of your critique (sharpened of course by your brilliance). Love drives your will and gives you energy, and your brain steers it. It is admirable in itself, and even more so in your ability to reflect on it and acknowledge it openly. Love — and yes, prayers — going your way.

—Myra Ferree, December 2, 2018

???

—Stefan Svallfors, December 3, 2018

I am given to terrifying daydreams of tragedy befalling our family. These often focus on the children, and I find myself imagining anything and everything that would go wrong. There was an article in the Week recently that suggested these gruesome fears are experienced by many parents of young children and may be a way in which our minds (and bodies) coax us into the state of "hyper-vigilance" required to care for human infants. I have taken comfort in this hypothesis lately, and I have tried to be grateful for the knowledge and awareness these dark visions deliver and promote. Thank you so much for sharing this dream and reflecting on it so sensitively.

—Adriano Shaplin, December 3, 2018

My mom used to superstitiously tell me that dream is the opposite of the reality. I think this statement applies in this case :)

—Dorothy Wu, December 4, 2018

The centrality of love in our lives. That is also what I have experienced in the path undertaken with my father. You are loved, you are love, Erik.

—Coline Ruwet, December 7, 2018

## A true fact (a bit R-rated) and a medical update

December 3, 2018

### A true fact

Everyone knows that one of the side effects of chemo is loss of hair on the head. We all have images of bald chemo patients. Men tend to display their bald heads; women often want wigs or use scarves to deal with baldness. Some, like me, shave off all their hair before they are completely bald just to see what it is like. Pretty cool I thought. But there is more to chemo hair loss than bald pates.

One of these is loss of inner nostril hair. Not a big deal, but if you tend to get a runny nose in the winter -- not as a cold or infection, but just a condition -- then the drip of clear liquid from the nose can become more or less constant with nothing to impede its flow. Periodic splashes of runny nose on the keyboard while typing. Constant reaching for tissues.

There is more.

Remember when hair began to grow in new places when you were an early teenager? Yes: pubic hair, nearly all gone. No big surprise there. But there is an aspect of this for us boy persons that I didn't expect, never

realized. Puberty also brought tiny hair follicles to the scrotum, the sacks into which testicles descend as Boys turn into Men (drum roll). I never once thought about this. Maybe this was because I never tended a boy baby; both our children are girls. Well those tiny hair follicles turn out to have a real function. They prevent the scrotum from sticking to the inner thighs. So, if you are a male (like me) and at night you sleep on your side (like me) or in the day you sit with your legs close together and crossed (like me), then when you get up and separate your legs, your scrotum is stuck to your thighs, kind of like the way silly putty sticks to things. Never thought I'd write a sentence likening my scrotum to silly putty, but so it goes.

### medical update

I had hoped to be discharged today. I had been told on Saturday that I needed 24 hours free of fever for discharge, which in practice means 36 hours. Well, I have been fever-free for over 48 hours. Unfortunately, a new complication has occurred.

There is a virus that virtually everyone has had since being a baby, CMV. Harmless in general, completely suppressed by even moderately functioning immune systems. But in post-transplant patients this can flourish and become a really nasty complication. So, the doctors test for CMV as soon as one has had a transplant. For a month my levels were undetectable. Then last week in the lab there appeared what was described as 300 copies of CMV in the relevant unit of blood (probably a micro-liter, although I didn't ask). That is not a level that poses any risk. The issue is whether it was rising and how fast. New tests were done last Friday the 30th, but the results were only available today. The level is over 4000, so treatment for this is needed. Alas, none of the treatments are ideal for the overall situation I'm in. They are all filled with side effects, including side effects on my immune system rather than just the virus in question. Nevertheless, I will begin later today taking pills to deal with the CMV. And this will require careful daily monitoring, so it was best to stay in the hospital.

One final reason I need to stay in Froedtert: the core new chemo I will be taking that will deal more aggressively with my nasty refractory AML has finally been approved by my insurance. It was just approved for my disease a week ago by the FDA, but the insurance company required more documentation. That drug, venetoclax, apparently identifies a protein in the AML white cells that is not present in healthy white cells, and while it suppresses all white cells, it does so more effectively for the leukemia cells. Or something like that. But, as usual, it has potentially serious side effects, so close monitoring is needed initially.

Thus, here we will stay for an indeterminate time. They say maybe we'll be discharged by the end of the week. I say, sometime next week. Place your bets. So it goes.

## Comments

Sending you and Marcia big hugs with all the love I have!

—Masoud Movahed, December 3, 2018

Gee, never thought about that -- the added function of hair follicles. Oye!  
Go venetoclax !!! Hang in there Erik. Thinking about you and cheering you on. Jonathan

—Jonathan Patz, December 3, 2018



Funny. And less funny.  
xox

—Sarah Siskind, December 4, 2018

Wonderful, poetic imagery with the silly puddy Erik.

—Adam Szetela, December 7, 2018

## "What's the point?"

December 5, 2018

At the moment, the morning of Wednesday, December 5, I am feeling terrific -- negligible pain, inner calm, good enough energy, well rested. This is important to keep in mind: I can have a day like the one I report below which resolves itself into a feeling of wellness. But yesterday was something else. The story has four episodes.

### **Episode I. How not to figure out level of pain medicines.**

On Monday I was shifted from the IV Dilaudid pain medicine to oral medicine. This was part of a general move to get me off of IV medications which is needed for me to eventually be discharged. The issue then becomes the dosage, because the levels for oral are different from IV delivery. Dosage has two dimensions: how much (mg/dose) and how frequently (scheduled as every two hours or "as needed"). And then there is the monitoring for pain issue: should I be woken up to see what my pain level is on the 10-point subjective pain scale? I tried to explain to the night nurse that I had no basis for making a choice, since I didn't know the trade-offs among alternatives. I initially had a preference for no narcotics whatsoever, but once I was in the world of active pain-management, then I needed guidance, I needed someone who would give me professional guidance, tell me what the trade-offs were, etc. Instead, on the night of Monday-to-Tuesday, I had a night nurse who insisted on getting me to make a choice about everything every time. The night nurse was not one of my regular nurses but was filling in, and for whatever reason we couldn't get through to each other on this issue. Every time I was given pain meds I was asked to make choices. With one exception: my preference over whether I should be woken up to check on pain levels was ignored. The point of the pain medication is mainly to get me comfortable enough to sleep, so why wake me up to see where my pain level is on the 0-10 scale? All night like that. Somehow we never could sort this out. The next afternoon I had one of the best of my regular nurses. She shared all information and then made the choices for me when I asked her to. And now everything is going smoothly.

This episode brought home the complex issue around preferences and choices. This is such a salient thing in the current era -- the mantra of choice dominates the health care discussion, so people using Obamacare are required to go over alternative plans and make a choice. But to make choices with complex trade-offs when it is



basically impossible to have a meaningful understanding of what is in play in those tradeoffs is exhausting. (Single payer healthcare would solve this problem of course!!) The same goes for investment decisions and smart phones. Sometimes what is better than having unconstrained choice is having trust in someone who really knows what's important, what the risks are, someone who is really an expert and will act on your behalf. That is what I needed -- to be relieved of the burden of choice. I had one preference: to have my pain managed well-enough that it didn't interfere with sleep. Translating that into a dosage regime was something I was happy to delegate to someone I trusted who knew what they were doing.

## **Episode II. Intravenous Immunoglobulin (IVIG) and Rigors**

As part of the strategy to control the growth of the CMV virus I need a transfusion of immunoglobulin. This fluid is gathered from healthy adults and contains their antibodies which help repress all sorts of viruses. People with permanently depressed immune systems often get monthly infusions of IVIG. But it is very tricky to administer. Since nearly everyone is vulnerable to allergic reactions to something in the infusion, they load you up with pre-meds -- Benadryl + steroids -- and administer the transfusion at a very slow rate, only increasing the rate in small steps in light of the reactions. Well, yesterday all went well for the first 50% of the transfusion. Then, one tiny increment in the increase in rate and kapowie, I was hit with extraordinarily intense rigors. I was rigoring.

I have had one prior episode of rigors here which I reported on in the blog in the summer. Rigors (pronounced Rye-gors) is a condition of severe shaking with chills, bone-rattling shaking that seems uncontrollable. That is what I experienced in the summer. It was terrible. This time was much worse. I was sitting up when it started. In addition to the shaking all over I had muscular lock-down in my legs and torso and jaw. I could barely speak. I screamed out, I need help. My heart rate went up to a dangerous level. My breathing increased to rapid, shallow breathing. Marcia was at my side stroking my head, holding me, urging me to slow down my breathing and take deep breaths. I tried. I tried over and over, but I just could not control anything. Through clenched teeth I tried to say "I can't", but I wasn't sure anyone could understand me.

The nurses immediately sprung into action, and the PA was called to the room. They remained completely calm and outwardly just taking care of business. Later I commented on this and was told that inwardly everyone was tense and in high-intensity mode. Emotionally, for me, I am not sure what would have been most reassuring, more calming to my completely panicked emotional state: getting clear signals that the staff also saw this as a serious crisis and expressed this in their voices, or the extremely calm and matter-of-fact way in which their communications took place. For me, the world was becoming unglued, breaking apart. The pain was intense, but of a kind that suggested something could burst or collapse at any moment. But everyone in my environment was so cool headed. That was probably for the best, I am sure.

It took about 15 minutes for any alleviation of these symptoms at all. The transfusion was immediately stopped and I was given high doses of steroids, Demerol and Benadryl, all IV. The first administration of these didn't have an effect, but the second did. The shaking abated a bit and the lock-down eased off rapidly. By the time I was no longer rigoring, a half hour had passed, but it took a bit longer for my blood pressure, heart rate and other things to settle down. With all of the drugs pumped into me, I then drifted off to sleep.

## **Episode III. The IVIG Party**

Sleep, of course, was just what I needed. Some of my sleep was deep, but much was the kind of liminal sleep that moves back and forth across the boundary of being asleep and awake. The boundary is one in which I felt I was simultaneously awake and asleep rather than simply "half awake". I had, repeatedly over three or four

cycles of this, the following conversation with Marcia:

"Where's the IVIG Party?"

"What do you mean?" Marcia asked.

"We were at the IVIG Party, " I said in all seriousness. "The men were all wearing tuxedos and the women poufy dresses that made loud crinkly sounds when they walked around. You were wearing one of those. We need to go to Chicago for the rest of the Party"

"Honey, we're in Froedtert Hospital in Milwaukee, " Marcia patiently explained. "you're here for treatments for Leukemia."

"I know that!", I replied with some irritation. "But where's the party?" In my dream-mind we were in the corner of some vast warehouse-type room. In the distance was a party, with men in tuxes and women in crinkly. There were also giraffes at the party for some reason.

Marcia stayed by my side, stroking my head. "It's OK. We're in Froedtert"

"We need to go to the Party. But what's the point? What's the point of the Party?"

I drifted back to sleep.

I woke up. "What's the point of the Party?"

Marcia suggested that we could sort that out tomorrow.

Gradually over several cycles of this, my confusions dissipated. I no longer had any delusions about the party. All that was left was the question, What's the point? But that was clearly a question about leukemia, not the party.

What's the point of leukemia? That is a really stupid question. Our human effort to cure the disease has a point -- a purpose laden with meaning -- but the disease itself isn't there for a purpose.

#### **Episode IV. Aftermath**

I slept beautifully last night, even though my night-sweats have returned with vigor (five t-shirt changes last night). My peaceful sleep may be due to all the drugs I got yesterday afternoon to deal with the IVIG rigors, but those should pretty much be completely out of my system by now. In any case, for whatever reason, today I am at-ease physically and mellow in the aftermath of yesterday's intensity.

The main immediate concern ahead lies in getting my white cell count down in order to control the blasts and significantly reduce the enlargement of the spleen, which would also eliminate the spleen pain. The delicate trick here is to do all this in a way that minimizes harm to my new transplanted immune system.

## **Comments**

SO relieved that this frightening and painful episode was followed by ease and restored well-being. Whew.

I really appreciate what you had to say on the issue of choice. I've had a number of difficult experiences of this sort, the worst being when I was asked just before surgery for skin cancer which of two approaches to dissecting my nose I'd prefer. Good grief. Thank you for articulating the problem so clearly.

Sending much love!

—Cathy Loeb, December 5, 2018

Oy. What a story!

—Sarah Siskind, December 5, 2018

oh my god, Erik, going through this with you is incredible. You are so good at describing it that my heart races and drops, races and drops, with every sentence. Sandy and I sending love continually - Jenny

—jane mansbridge, December 5, 2018

I feel for you!

—Marianne Ahrne, December 5, 2018

A party with giraffes? What a wonderful image (although I admit I prefer watching them lope across the veldt)... I am really glad to hear that you felt better today. Sending much love!

—Gay Seidman, December 5, 2018

I tried replying to Gay's comment about the giraffe, but I lost it somehow. Anyway, that is for another time. Glad things have stabilized sort of ... And the giraffes and folks in formal dress have gone home.

—Mary Jo Maynes, December 5, 2018

Erik, I'm so glad you had a restful night and are feeling good today. You make a difficult journey sound like an adventure.

—Adam Gamoran, December 6, 2018

## Back on Track!

December 6, 2018



No drama today -- what a relief. Everything has stabilized. The new chemo medicine, venetoclax, has finally arrived, all obstacles overcome, and I just took the first pill. This is the chemo that was just approved by the FDA for AML and is supposed to block cell division for cells that express a particular protein (or something like that). This turns out to differentiate between my donor white cells and the cancerous AML white cells. The head of the HemOnc team, Dr. Michaelis, also decided to restart the new chemo infusion that had been interrupted by my fever last week, decitabine, which I will get as an infusion for five straight days simultaneously with the venetoclax. This is going after the core disease processes "with all guns blazing", knowing that there will be side effects to deal with, but wanting to get on with the central task of this battle. (Again: in spite of my values, I can't see how to avoid the military metaphor. It seems to fit the symbolic realities of what is going on in my body, so I'm not going to worry about it any more). I expect therefore to be sicker in the days to come -- hopefully nothing like the previous few days, but sicker nevertheless. I should have some tumor lysis -- the dying off of tumor cells. If this occurs too rapidly you can have a draining off of electrolytes, which can cause havoc with kidneys especially. Rigors is also listed as a potential side effect, but certainly not as intense as on December 4th, and in any case I don't think would trigger the panic I experienced then. So, once more into the breach! I'm excited.

### Visit from Jenny

I had a wonderful, deeply moving visit from Jenny and Mark this afternoon. They are staying at our house in Madison while Mark finds a job in Atmospheric sciences. It works perfectly that Madison can be a base of operation and that Safira is in a fantastic Montessori preschool program. Becky and baby Ida are coming for

three days starting tonight, and Jenny will come back for a visit with Safira on Saturday. So I will be engulfed with the presence of my two daughters and two of the three grandchildren. The best medicine possible.

## Comments

Great. Thanks for the good news. Love, Peter

—*Peter Rosenthal, December 6, 2018*

I am so delighted to hear that things are back on track, dear Erik! I am also jubilant that you will be surrounded by all your wonderful family (and of course, the wonderful grandchildren) in the next few days: the best medicine, indeed!! Sending you and Marcia (and the entire family) big hugs with much, much love!

—*Masoud Movahed, December 6, 2018*

that's good news overall. Hope the period of intensified symptoms/reactions/side effects is as brief and easy as is consistent with winning the overall battle.

—*Myra Ferree, December 6, 2018*

Lovely picture. I hope the side effects are not too bad.

—*Pamela Oliver, December 6, 2018*

That all sounds very positive. All our love and best wishes to you and the family. Children have a magical way of lifting everyone's mood and spirits.  
xxx

—*Janeen Baxter, December 6, 2018*

Hello, Erik,

It's good to hear that you're stable and back on track. I hope the venetoclax works and has few side effects. Most important, I'm glad you're surrounded and supported by your family. I'm sure those grandchildren bring great joy! I think of you often.

—*Charlotte Frasca, December 6, 2018*

So moved both by your hopeful spirit and the photo of you and Jenny. Love it. Thrilled you'll see both girls and their girls. Sending love!!!

—*Kathy Cole-Kelly, December 6, 2018*

Erik plus Jenny picture so nice. Matching smiles. Plus I like seeing the top of your head. Tumor lysis--hopefully this is part of what we are experiencing politically. Your experience seems like a metaphor for the body politic in a Black Mirror episode. Counting on you. Inspired by you.

—Nancy Folbre, December 7, 2018

## quick update & a wonderful day

December 7, 2018



**medical update.** I am now in full bore attack mode with the new chemo combo. So far no noticeable side effects. There are only two things I've been contending with: high potassium & mild constipation. The high potassium is a problem because it can trigger heart rhythm problems, and given the episode of atrial flutter, we can't have that. I'm taking various meds to deal with that, but until the number comes down I have to wear annoying heart telemetry. As for the dreaded constipation, the "Poop Queen" (who proclaims she wears her crown proudly) has pretty much solved that by segueing me delicately from mild constipation to mild diarrhea



-- a fair enough switch in my book.

I will have a total of five days of the decitabine chemo infusion along with the venetoclax fancy chemo pills. After that I should be off the infusion for 22 days and hope to be discharged from the hospital. That would probably be on Tuesday, December 11. All of this is intended to fight the aggressive relapsed AML to create the environment for my engrafted transplant to function and start producing active T-cells to join the fight. If it were a spectator sport it would be exciting.

### **wonderful day**

Becky and Ida arrived last night and are staying in our little apartment 3 minutes from the hospital. The hospital ward also has a family respite room which we reserved for the daytimes of their visit. It is wonderful --comfy seating and couches for naps, totally quiet, and with shades down, dark for Ida to nap, with a private bathroom. We spent nearly all day hanging out. This time, like my visit with Jenny yesterday, is the deepest happiness for me; happiness all the way down, unsullied by the health difficulties and the prospects of dying. I'm surprised by this in some ways. I desperately want to live. But I also could not feel more fulfilled and happy than I do right now in this present moment. I am not saying that the prospect of dying never interferes with my happiness, but not yesterday and not today.

## **Photos**





## Comments

I really appreciate the way you write this. Really appreciating the moments. I hope this isn't too creepy but it seems to fit. I can't remember exactly the source, but there is a lot of mystical discipline that stresses "remember every day that you will die." i really hope you live a lot longer because you mean so much to so many people. But you are also reminding all of us that we should all remember every single day that we will die, and that in remembering that, we remember how to live. I know you are not personally religious and that is fine but I still say, you are a blessing to us all.

—*Pamela Oliver, December 7, 2018*

You have a commendable ability to live in the moment, by which I mean to inhabit the days and hours fully engaged in the experiences they offer. I'm glad these are happiness ones right now, but the same full-on awareness is visible in the miserable ones too. That is what I think of as truly living as opposef to letting time pass or worse yet killing time.

—*Myra Ferree, December 7, 2018*

I am so glad that Ida is allowed to see you, how wonderful!

—*Gay Seidman, December 7, 2018*

Your spirit shines through, dear Erik! And your fortitude in this challenging time is so inspiring to all of us. Sending you and Marcia (and the entire family) so much love.

—*Masoud Movahed, December 8, 2018*

Wonderful meditation about the présent moment ; The only present there is in life. The pictures of Ida and you are a shining testimony of this experience. We do not know the shape of the future indeed. I pray for you to become even more immersed in the present and not to worry about the future. Thank you for leading us there. love and peace of mind

—*Isabelle F., December 8, 2018*

I love the way Ida is looking up at you in the second photo - so sweet! Love to all!

—*Mary Jo Maynes, December 8, 2018*

## Unglued and reglued

*December 8, 2018*

I keep trying to figure out exactly how I can feel such total, deep happiness at the moment given my illness and that I am not in denial about its prospects. I don't quite have the words to describe the feeling. I know about "resilience", about the unity of mind and body or emotion and body (although that could just as easily evoke despair), about "compartmentalizing" certain feelings. I talk about these things, say these words, and they tap into the reality/unreality of what is happening, how I'm feeling, but they do not convey things fully.

This weekend Becky is visiting with Ida. Jenny came from Madison this afternoon, but Safira had a runny nose so she had to stay home. We hung out in the wonderful family respite room much of the day. Marcia, Jenny, Becky and Ida and me. I went on and on about love, fullness, happiness "all the way down", and how this was unsullied by the physical state I was in or the prospects of dying. Then at 3 p.m. I needed to return to room 31 for my chemo. I stood up. It is a two minute walk. I suddenly felt unglued. That is the word and image that came to mind. Like there was a wall with nicely-glued seams that started to leak and then began to burst — a wooden wall that was also a dam of some sort. It burst and I was overwhelmed with emotion — a *flood* of emotion? I was walking ahead of Marcia and staggered down the corridor. Spleen pain once again. I had been trying to stretch the pain medication. The pain was not all that terrible, but it played into the inner sense of things falling apart. I fell into bed. Soon the intensity subsided. The emotional flood retreated. I slept a little and awoke reglued.

This isn't in any way shocking, certainly not surprising, or even disturbing. I *am* deeply happy, and I *am* deathly ill. That is the reality/unreality in which I live. Maybe there is nothing more to figure out.

## Comments

Erik- Your emotional clarity and honesty are a gift of learning for a whole community of people. I am so happy to know that you and your family are together right now. Sending love...

—*jeannette golden, December 8, 2018*

It is just so delightful to read this post, dear Erik! Delightful, because you feel very happy as your wonderful family is around you. Your happiness makes all of us very happy. Sending you and Marcia all the love I have!

—*Masoud Movahed, December 8, 2018*

Ciao. I see happiness in all the love you foster among those who are physically near to you, but also in those of us, who are far away.

—*Donatella Della Porta, December 9, 2018*

Thank you for sharing it all... the sadness, the fear, and the expansive joy. Much love!

—Cathy Loeb, December 9, 2018

Your honesty in all things is appreciated, here as much as in your scholarly writing. I, too, feel different waves of emotion in the same day, or even the same hour. It's part of the human condition, and I suppose it's a natural response to the real complexity of our lives--and our world. I hope that you at least get to watch some schadenfreude TV this morning, as the beginning of the end has arrived for our President, currently known in Mueller-speak as "Individual #1."

—John Gastil, December 9, 2018

## Busy day

*December 9, 2018*

My Day:

1. Hung out with Joel, Becky, Ida & Marcia for an hour or so in the morning. Talk about politics, the collapse of the Wisconsin model of decent state level progressive politics, but in spite of all that, the sources of hope and even optimism.
2. mini-nap.
3. Went for a half-mile walk around the CFAC8 corridors with Becky
4. Delicious Mini-nap in room with Ida chattering away.
5. More general hanging out with Becky and Ida, and marveling at the weirdness of feeling so happy and content
6. Chemo infusion and chemo pills. Still no relief on spleen pain, but white cell count down. Potassium is also declining so perhaps I'll be disconnected from telemetry tonight.
7. Nearly two-hour skype seminar with a reading group of Canadian activists in which David Calnitsky's younger sister, Shauna, is involved. They read the final version of my *How to Be in Anti-capitalist* book. The session was beautiful, completely absorbing and inspiring for me. It felt wonderful to be in such deep dialogue with young activists. I was asked how I managed to remain so optimistic and hopeful. I said it was an interesting question at this specific moment because optimism/hope refers both to my body and to the world. I explained why I disagreed with Gramsci's aphorism about optimism of the will and the pessimism of the intellect -- without some optimism of the intellect it wasn't possible to sustain optimism of the will. Besides, it is too easy to be pessimistic -- there is no intellectual challenge there. Optimism takes work!
8. Took shower.
9. Wrote this blog.
10. Time to watch an episode of *The Marvelous Mrs. Maisel*.

## Comments

Indeed Erik, optimism does take some effort. I am so glad to read that you are feeling much better. As always, with lots of love and the best wishes for you, Marcia, and the rest of the family

—*Mansoor moaddel, December 9, 2018*

Watching Mrs. Maisel in parallel!

—*Cathy Loeb, December 9, 2018*

Erik, I really like your comment, "Besides, it is too easy to be pessimistic -- there is no intellectual challenge there. Optimism takes work!"

You know I'm asked about my views on climate change all the time now. Will be quoting you a lot more.

—*Jonathan Patz, December 9, 2018*

Go, Erik!

—*jane mansbridge, December 9, 2018*

## scattered things to talk about

*December 11, 2018*



It is a brilliantly sunny, cold winter day in Milwaukee, early in the day with the sun low in the horizon. I won't directly experience this weather; I am in my cozy room on the 8th floor of CFACF looking more or less to the South. Yellow warm glow.

### 1. Sunday's skype seminar

Marcia remarked that when I get into an animated discussion with students, especially around abstract theoretical issues in sociology, I often shed my exhaustion. I have had a number of recent visits from students past & present, and colleagues that went this way. We'd begin with catching up, me talking about my illness; students talking about what's going on in their lives. Wonderful to reconnect, to share, but I would feel the limits of my energy. Then we would drift into a theoretical discussion -- about functional explanation in World Systems theory or the contradictions inside of the state, or the implications of taking seriously the idea of inescapable dilemmas, and suddenly my energy level would increase the more intensively we would talk. Sunday was like that (see group photo below.) It is the reason I can still imagine in spite of everything that I might be able to teach a grad seminar next semester.

### 2. Singing on the floor with Ida.

This past weekend was a completely glorious immersion in the life of my youngest grandchild, Ida. She was not allowed on the cancer ward itself, but just outside the doors to the ward, by the elevators, is a small family respite room which can be reserved. This is in addition to a large family lounge with a big LED TV and comfortable chairs, big round tables for games and other things. The respite room is small, but large enough for

three couches for naps plus a recliner plus floor space to lay out a blanket for a baby to roll around on. The room has blackening shades and dimming shades and a private bathroom. We reserved it for the whole weekend, but said we could be displaced if there was a more pressing need. We basically set up camp there for the weekend, and this made possible such a deep, relaxed, meaningful time for me. Attached below is a snippet of my singing the last part of my song to my grandchildren, lying on the floor with wee Ida.

### 3. Attack of the Kleenex box.

This is a true story. To get discharged there are two main tasks along with some minor ones: getting the pain under better control, and getting my bowels back to a more regular rhythm. These were connected insofar as the pain management involved opioids which are constipating. As I have written before I have been very reluctant to use any opioids, but I am now a convert to good pain management. I have gradually accepted new forms (for me) of pain medication, and each time the added relief was significant. Yesterday afternoon the palliative care doctor convinced me to use a fentanyl patch -- "Don't worry," she said, "it is NOT that fentanyl" -- and unquestionably it is an improvement. I have reduced the Dilaudid and I really feel good, I'm back home in my body at ease, and without any loopiness. So I'm on tack on the pain issue. But then there is the constipation, the dreaded locking down of the gut. All opioids are seriously constipating. That was the original reason for my strong no-opioids injunction and the reason the Poop Queen has pursued such an aggressive prophylactic anti-constipation strategy.

Well, as I think I wrote a few days ago, that strategy got torpedoed by the floor doc on the weekend who canceled the prescription for Senna since it had triggered diarrhea. This was the first significant breakdown in good communication with docs over the 8 months I've been in treatment. Since then we have been working hard to undo the mistake: miralax, triple dose Senna morning and night, hydration, and some other concoctions.

What does this have to do with a Kleenex Box, you might well ask. Well, at night I prop up a Kleenex box against the railing on the right hand side of my bed so I can find it in the middle of the night. It was about 4:30 a.m. this morning. I was sleeping very soundly and, it seems, I had gradually scooched over to the lurking Kleenex box, to the point where the sharp corner of the box was pressing against my forehead. Suddenly I crossed some tipping point and woke up with a shriek. Marcia leaped out of her bed and came to my side. There was a big dent in my forehead. In the darkness she couldn't tell what had happened. "Eriki, what happened?" she asked with some alarm. The pain instantly subsided, but the dent continued. I sat up, probably said something about the Kleenex box attacking me, got out of bed and went to the bathroom. And dumped a load. What sweet relief. The next day I told the Queen of Poop that she needed to add to her strategy of constipation management, attacks by Kleenex boxes.

### 4. What what Whatwhat whatwhatwhat What?

Prior to my illness my hearing was pretty good. Judging from the preferred volume of the TV, Marcia's has been in the slow slippery-slope decline for some time, the fate of most members of our species. Since my illness, alas, my hearing as well seems flukey. Its a bit like coming in for a landing in an airplane without being able to clear the tubes out. The result is that the most frequent word used between us in our little world is "What". This is especially the case at night when I am in my hospital bed and Marcia in her couch-bed. I sleep on my right side so my right ear is on the pillow. My right ear has, I think, a bit better hearing than my left ear. So when I'm snuggled down I often miss 50% of what Marcia might be saying. What? What did you say Marcia?

## Comments

Ida's singing with you!

—*Beth Wright, December 11, 2018*

Ida is so adorable. You are very lucky to be her grandpa, professor. And she is very lucky to be your granddaughter!

—*Kerem Morgul, December 11, 2018*

The beautiful Ida with her beloved grandpa singing together - how wonderful!! Sending big, big hugs -

—*Masoud Movahed, December 12, 2018*

Many of us will be \*overwhelmed\* with excitement if you teach next semester!

—*Adam Szetela, December 14, 2018*

## An extraordinary moment

*December 12, 2018*

Yesterday early evening I had one of the most extraordinary conversations of my life. The head doctor of my hematology oncology team. Laura Michaelis, had been away for a few days at an important annual national meeting. This was our first encounter since she got back. All told, we probably talked for nearly an hour. She noted how awful the rigors incident had been and said that I would not be subjected IVIG treatment again.

I then said to Laura, "That wasn't my worst moment since being here. I also had the most horrifying dream of my life." I then told her about my nightmare of December 1. Here's what I wrote in the blog on December 2, the day after that dream:

"I was hesitant to write about this incident because it is so hard to put it into words and it was so powerfully disturbing. I was sleeping yesterday afternoon and had an extremely brief dream snippet, not a full-blown dream with a narrative structure. The whole thing probably lasted a second or less. It was a malevolent scene, not a story: I opened a door to a room that was filled with everyone I love and who loves me -- all my immediate family, grandchildren, extended family, friends, students, colleagues. Everyone. And they were all laughing at me, mocking my efforts to understand my illness in my blog, saying I was ridiculous. There were no words but there was an instantaneous conveyance of meaning. I let out a scream and woke up sobbing, gasping. This, I feel, was the worst nightmare possible -- the very foundation of my life, love, became empty. I have firmer beliefs in the love I experience in the world than in my critique of capitalism. If love is false, there is nothing, nothing."



Laura then quietly said, "You know Erik, I am a devout Catholic. This is just what Jesus said on the cross during the crucifixion: *My God, my God, why hast thou forsaken me.*"

These are perhaps the most important words Jesus spoke in the central narrative of the crucifixion. I imagine they are the words from the Gospels that are most familiar to people. We were both crying, but continued to talk. The deep parallel between Jesus's deepest moment of despair and mine was profound. I'm sure that my unconscious was not tapping into these words from scripture in my dream; they were a direct expression of a universal fear -- utter, total abandonment by the most fundamental source of meaning in one's life. The Christian God is the God of Love; or perhaps as some Christian's would express it, God IS Love. Jesus's despair is therefore: why has Love forsaken me. "If love is false, there is nothing, nothing", is how I experienced this.

## Comments

Betsy and I are following you

—John Posner, December 12, 2018

Betsy and I are following

—John Posner, December 12, 2018

(Especially Mahayana) Buddhism and its focus on loving-kindness, compassion, inter-connectedness and non-self are also closely connected to all of this. Mainstream US mindfulness generally does not engage with these issues.

<http://www.pbs.org/thebuddha/blog/2010/jun/3/buddhas-love-melvin-mcleod-interviews-thich-nhat-h/>

—Emanuel Ubert, December 12, 2018

My heart goes out to you, Dear Erik! Sending you all the love I have - you mean so much to all of us!

—Masoud Movahed, December 12, 2018

This followup to your dream is even more powerful than the dream itself. I had tears in my eyes reading it. Without love, we are nothing.

—jane mansbridge, December 12, 2018

In particular, I am so grateful for the quality of dialogue that you have with your doctor. The level of attention And presence she maintains to your true self, and not just a body to cure, is wonderful. I pray for the two of you.

—Isabelle F., December 14, 2018

## Medical update: no discharge

December 14, 2018

I was all ready to be discharged this morning when my fever jumped across the 100.4 F line. I haven't had a fever in weeks, the number mostly sitting happily in the 97s and 98s. Then last night I had a reading of 99.1F. Not to worry, the nurse said. Next reading was back to 98.7F See, nothing to worry about. But I had seen this pattern before: a bit of instability, a little rise, then we cross the threshold. That's what happened. In mid-morning the temperature went up to 102F. No ambiguity there. So, blood cultures had to be drawn afresh. Sepsis is one of the ways to die from leukemia and the doctors don't want to take any chances.

The fever spike only lasted a short while — perhaps 20 minutes. Since then I have been back to the low variance condition. But I also felt really lousy for most of the day and so I wasn't unhappy being under the care of the ward.

It's late now; I need to get back to sleep. But I am finding that letting all of you know how I am doing is part of what makes me feel so connected to everyone, and so even a brief update feels good.

## Comments

Hi Erik

Great to get these updates and helps us to feel connected with you. Sorry to hear about the fever but sounds like it is under control again.

Much love

Janeen xxx

—Janeen Baxter, December 14, 2018

Your posts make us all feel connected to you, and so YES, even a brief update is deeply appreciated! xoxo

—Cathy Loeb, December 14, 2018

Dear Erik,

Lennart shared the unfortunate news of your illness, and a link to your blog, so I thought I'd stop by and say hi, and that a lot of us in Lund are of course thinking of and rooting for you! Chad, David and I (who you may remember from our nice albeit brief pub session) all finished our PhDs earlier this year, and David and I recently picked back up with our ambition to write an article on emancipatory social science and sustainability research (building on our use of it in our respective PhDs). I hope it brings you some joy to know that we continue to be inspired and enriched by your ideas.

All the best,  
Ellinor

—Ellinor Isgren, December 14, 2018

Keep fighting, Erik!

—Paul Dudenhefer, December 14, 2018

## medical update

December 16, 2018

I'm bit ragged around the edges as we are trying to get so many "numbers" and conditions into their proper place. I'll update you on these things here and then, tomorrow talk about some interesting (for me anyway) new thoughts about various aspects of my treatment and Life at Froedtert.

*Sodium.* My diabetes insipidus continues to mess with my sodium levels and we keep oscillating between different strategies to deal with this. Yesterday I went 36 hours without a dose of desmopressin and ended up peeing 40 times in an 18 hour span with a constant terribly dry mouth and unquenchable thirst. But of course nearly every medicine I am taking lists "dry mouth" as a possible side effect. My sodium had been as low as 129 and then had risen to 135, the edge of the normal range.

*Pooping.* Dealing with constipation is also a perpetual theme. I am not backed up with hard lumpy stool, but I am still backed up. Yesterday evening we threw everything at the problem: Senna, Miralax, Lactulose. Gurgling occurred but no action. At 2:00 a.m., to check out an issue connected to the diabetes insipidus, the night nurse did a bladder scan -- basically kind of a portable echo scan using a wand -- to see how much urine I still had in my bladder once I had urinated. That involved pushing a wand with some pressure over my lower abdomen and bladder. This triggered significant cramps. "Gotta get to the bathroom" I proclaimed. I made it, and after some preliminary tooting, I dumped a massive load. The doctors wanted to be able to evaluate event, so they had put what they call a "hat" in the toilet to capture the stool. It was filled to the absolute brim and looked like pudding. The nurse went in and proclaimed "Wow". I asked if by nursing standards this was impressive. "You betcha".

*Potassium.* That had been rising, which raises potential problems with cardiac arrhythmias, but now the level seems OK.

CMV. Childhood virus that virtually everyone has. Often this becomes a problem with post-transplant immune systems. IVIG is used to treat it, but that is now off the table because of my reaction last week. Ultimately restoring an immune system will be the way to treat it. The viral load of this particular problem had been cut in half, but this is not yet "under control." That will get remeasured tomorrow.

*White cells, neutrophils, platelets, and hemoglobin.* Then of course there is a issue at the heart of my illness: white blood cells. That is what the chemo is dealing with while trying to keep platelets (for clotting) and hemoglobin up. So far, almost every day I need a transfusion of blood products.

So, you can see, there is a lot going on, lots of interacting moving parts. I think once I am fever free for a few days and they feel I am in some sort of rough equilibrium on these various concerns, I will be discharged. I'll know more tomorrow.

## Comments

Hang in there Erik. And with all the complexities, the ability to keep balancing things gives me reasons for optimism.

Wishing you all the best in the coming days!

—Jonathan Patz, December 16, 2018

Love the poop description!!!! Hugs - J

—jane mansbridge, December 17, 2018

## meandering thoughts on artificial happiness and lemmings

December 18, 2018



## Happiness: authentic versus artificial?

This is going to be a winding account of a particular moment of emotional volatility. This seems like the best way to write it, especially given my current fatigue level -- I keep falling asleep while writing, so I'm constantly stopping and starting, which makes this a bit disjointed.

There is a longstanding issue in philosophy around the concept of happiness that concerns the vulnerability of this idea to various forms of manipulation. In Marxism this is reflected in the critiques of "job satisfaction" in analyses of alienation: workers may say that they are satisfied with their jobs because the range of alternatives is so limited that what they have seems pretty good compared to the alternatives. Workers on a production line with the high division of labor ought to be unhappy. People are prone to adaptive preference formation -- the sour grapes story in Aesop's fables. And then there is the "happiness pill" problem: a pill could be slipped in the water supply that was completely undetectable and would make everyone feel profoundly happy, except when there were good, objective reasons to feel sad -- like with the death of a loved one. Would the world be a better place with a happiness pill in the water supply?

I have engaged these issues a bit in my discussions of social justice. I have framed a just society as one in which "all people had equal access to the social and material means necessary to live a *flourishing* life." I didn't say "...necessary to be happy". Of course, being unhappy interferes with flourishing, so the practical significance may not matter so much: the social institutions which are conducive to access to the conditions for happiness will also be conducive to flourishing, but I felt that happiness was a more superficial cut into the problem. This is overlain with the problem of the "happiness industry", the commercialization of easy ways to be happy, from recreational drugs to hyper-consumerism.

A different angle: In talking with Janet about meditation, she recently suggested that I meditate on a feeling of wellness rather than on eliminating the sickness, more specifically, a feeling of wholeness and bodily contentment. So I've been doing this. And I've been writing in the blog about how thoroughly happy I am and how this is unaffected by how miserable I might be about the disease.

On Friday night I woke up around midnight, and wrote Janet this email: "Dearest Janet, I drifted awake this evening with a full and profound feeling of wellness, I was sleeping deeply, peacefully. I didn't wake up abruptly, but slowly. No sense of discontinuity between me and the world -- really at one in the ways we've talked about. So sweet."

The next morning I was talking to Marcia about various things. I'm not sure what the trigger was, but I suddenly started crying. It seemed to me out of the blue -- tears and sobs without focus. To comfort me Marcia looked up the side effects of the dilaudid pain medication I'm taking. One side effect listed was dysphoria, a feeling of sadness and unhappiness. But also listed was euphoria, deep feelings of contentment. Medication that would eliminate the first of these (dysphoria) would be a good thing. I deeply believe that depression and other disruptions of our ability to enjoy the world are a real source of suffering and are often to a substantial extent neurochemical in their causes. They should be treated like other ailments that interfere with healthy functioning. No one should feel stigma for taking an artificial hormone spray to deal with diabetes insipidus; the same applies to various kinds of antidepressants. Fine. That is absolutely clear to me, but somehow when I heard that my feelings of profound and pervasive happiness and contentment were also potential side-effects of dilaudid, I felt threatened.

I know this doesn't make sense -- I had been writing about my feelings of happiness long before I took any

dilaudid, so at most the dilaudid intensified feelings already present. But I am not talking here about a rational assessment, but of what I experienced. I was proud of my resilience in the face of AML; I felt that the equilibrium I reached was a real *achievement*, not some pharmacological trick. It is one thing to say that the reduction of pain as such contributes to happiness since pain renders one unhappy; what was disturbing was hearing that some of my more profound contentment as such might be coming directly from the pain medication. This somehow made me feel cheated out of an authentic experience of those emotions.

### ***A lemming named Bubber***

For the past week or so, Marcia has been reading Alan Arkin's wonderful book, *The Clearing*, to me at night. The story revolves around a superb character, Bubber, who happens to be a lemming. He is terrified of being a lemming because of their reputation for jumping off cliffs, but he doesn't find simply becoming an unlemming a satisfactory alternative. This resonates with the real utopia theme of seeking a positive alternative that is not just a negation of something, but a full bore affirmation of positive values. I first read this book 30 years ago. It is gloriously funny, and a really terrific book to read out loud, but also I think, a deep rumination on meaning. A ten year old and a seventy year can both enjoy it. It surprises me that it is not seen as a classic piece of allegorical literature.

Anyway, one of the themes of the book is that each of animals in the book is seeking their inner "lion". Only one of the critters believes she has found her lion, Marion the duck. She's not completely certain of this, but the other animals in the clearing are pretty sure this has happened. Lots of discussion of what this all means. Bubber is always confused, but this is mainly because the world is so consistently absurd.

Well, last Friday Betseygail was visiting from Texas and while walking across an open field between our apartment on Glenview avenue and the hospital, she found a little toy lion (in the photo below). What a deliciously remarkable coincidence.

## **Photos**





## Comments

I can see exactly what you mean, and it IS puzzling. I think achieving that sense of wellness WAS an achievement. Can it be an achievement if it was all caused by the drug? No, it can't be. So if it was all caused by the drug it wasn't an achievement. But I can't believe it was all caused by the drug. I've been reading what you have written for a little while, and probably the most important part of it for me has been the energy and intelligence you've put into understanding what is going on and taking yourself, as close as you could at any point, to the best available possible place. 'Role model' is an overused word, but you have been a role model for me. I've learned a lot about what to do if I find myself in a similar place, and even what to do right now, just plain old in my life. So I know it has been an achievement, because I've watched it evolve, before the drug. Now supposing the drug was 100% responsible for the "happiness" feeling. (Unlikely, but take it as a supposition.) It could not have been 100% responsible for the "wellness" feeling. Because the wellness feeling was what you and Janet had created and what you had created without Janet. I think it's like the difference between flourishing and happiness. And maybe it is, in fact, a form of flourishing, so it's not just an analogy but actually the thing itself. The drug might possibly have made you happy. But you made you flourish. Strange to talk of flourishing when you're so ill, but in a deeper way you are flourishing, and growing, and expanding. And, I have to say, helping us flourish, grow, and expand with you because of this blog. Thank you. - Jenny

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—jane mansbridge, December 18, 2018

Hi Eric, I really enjoyed these meanderings on happiness. I just returned from a day at Memorial Sloan Kettering where I had my bi-monthly MRI and Cat Scan. Often I use this time to meditate on the people I love and the things I love about them. Today I thought mostly of my daughter, Marta. This often leads to feelings of euphoria. I am presently reading "How to be Sick: A Buddhist Inspired Guide For the Chronically Ill & Their Caregivers" by Toni Bernhard. There is a fair amount in the book on finding joy. I'm now motivated to read The Clearing. Thanks! Lisa Reticker

—Lisa Reticker, December 18, 2018

I especially enjoy the two comments shared today as an echo to your profound blog entry. Thank you so for these insights, wisdom, sharing and indeed contribution to our own flourishing and' happiness.

—Isabelle F., December 19, 2018

Many thanks Erik for sharing your reflections on happiness.

May I also take this opportunity to wish you and your family a very merry Christmas, happy, and healthy new year.

—Mansoor moaddel, December 19, 2018

## medical update

December 19, 2018

My health situation has deteriorated over the past two days. It makes me feel that I had a pretty glib view of being miserable, and a nuanced way to talking about happiness and wellness before. Here's the situation: After a CT-scan of my abdomen yesterday, two things were discovered, (1) a mild splenic infarction, resulting in the death of some spleen tissue; 2) an infected part of my colon. The splenic infarction is like a heart attack, only in the spleen. Part of the spleen was enlarged to the point that it did not receive adequate blood and eventually dies. That is part of where the spleen pain comes from. The infection is more worrisome because it could lead to a rupture of the colon which in turn could lead to sepsis, one of the ways AML could kill me.

As a result I have been taken off all food and drink by mouth. I get hydrated intravenously, and so far only get nutrition in a minimal form. I just returned from intravenous radiology where I got an extra connector added to my PICC line through which a concoction that is more like "food" can be administered. At the moment I'm famished, not having as much as a glucerna or anything else for three days and constantly parched. When I wake up my lips are glued together and I have zero saliva a loosen tings up. I'm allowed to sip some water and

swish it around, but told absolutely not to swallow anything. Apparently water in my bowels increases the risk of rupture.

The overall result of this is tat I feel CRUMMY. That should be a dance set to the Bernstein's song "I Feel Pretty" from "West Side Story:" "*I feel pretty, oh so pretty*" would become, "I feel crummy, oh so crummy."

I have to stop now. There is much more to write, but I'm exhausted, really spent. Marcia is in Burlington, Vermont, where she has been helping her Dad get settled in a Hospice Residence. Cathy and Jeanette spent the night with me last night, which of course was not necessary but incredibly sweet, and Gay will take over from them now. So, good night.

## Comments

Sending some comfort your way!

—Annabel Ipsen, December 19, 2018

Eriki, we are so sorry to hear how crummy you feel. We love you so much and sending you out love always. Hope to visit you soon if/when that works for you. xoxoxo

—Lisa Baker, December 19, 2018

sending non-crumminess your way!

—Debra Satz, December 19, 2018

Oh boy that stinks! It will be amazing when you pull through all this. xo

—Sarah Siskind, December 19, 2018

Dear Erik,

I am so sorry to read about your health situation. You are in my thoughts. Don't you feel lonely; there is a whole army of well-wishers behind you.

With lots of love

Mansoor

—Mansoor moaddel, December 19, 2018

You have my love and my prayers with you, Erik!

—Amelie Davidson, December 19, 2018

Oh Erik. That sounds terrible. I hope things improve quickly and they can sort this out for you. All our love ,  
Janeen xxxx

—Janeen Baxter, December 19, 2018

Dear Erik. I'm so sorry to hear this. We all send you our love and are thinking of you. Mark.

—Mark Western, December 19, 2018

CRUMMY is the word!! Also Aargghh! You will prevail!

—Mary Jo Maynes, December 19, 2018

Sending much, much love from Jenny and Sandy!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!

—jane mansbridge, December 19, 2018

I suspect your "I feel crummy" threshold is exceptionally high, which means your body must really feel like it's in the wars at the moment. Much love to you, Erik! xoxo

—Madeleine Pape, December 19, 2018

A terrible, awful, very bad day and overall situation. Dry mouth is really much more uncomfortable than it sounds and you have got it really in spades. Hope they get the bowel infection cleared up soon so you can have some lovely water!

—Myra Ferree, December 19, 2018

Dear Erik,

Sounds really terrible. I'm so glad they're on top of it--but still...I hope you're soon much better! Sending healing thoughts your way.

ox-Sonia

—Sonia Baku, December 19, 2018

Sounds like you are deep in an involuntary meditation on suffering. How I wish it were otherwise. Continuing to hold you in the Light, sending lots of love.

—Margaret Vitullo, December 20, 2018

## ultra-mini update

*December 20, 2018*

**Pure self-interest instantly flipped into pure altruism. Phooey.** When I woke up this morning the first thing that came to mind was coffee. Strong, black, unadulterated coffee. I told Gay how Marcia makes good coffee here with our little drip machine. Gay dutifully did everything she was told to do, and poured herself a cup. "Just pour me a half a cup in the *The World's Coolest Grand Pa* cup," I said. The moment I said this, I realized I couldn't actually have any coffee because of the strict 'nothing by mouth order'. But where's the altruism now? The self-sacrifice? Giving up something so that someone else can flourish? Gay made the coffee; I hadn't exerted myself at all. Aroma. I now could smell the coffee but not drink it. So it goes.

Now for a quick update: feeling significantly better than yesterday, so in terms of feeling, moving in the right direction. Marcia will be back in half an hour. All of the numbers seem to be improving. So, maybe things are getting better.

## Comments

Thanks for the report. Glad.

—*Sarah Siskind, December 20, 2018*

We've been thinking about you non-stop since I got back last night. SO glad to hear you're feeling better and the numbers are doing what they're supposed to! Welcome back, Marcia!

—*Cathy Loeb, December 20, 2018*

It strikes me that the coffee making, although you couldn't drink, is along the lines of thinking of wellness as per Janet's idea. Just the act of letting your body/mind/energy go through the ritual of the coffee, which has wonderful associations, is a wellness message to your whole being. May the day be filled with magical moments of ease. Jody

—*Jody Whelden, December 20, 2018*

I am so delighted to hear about the update, dear Erik! Sending you and Marcia big hugs and much love!

—*Masoud Movahed, December 20, 2018*

Erik --

I've been following your ups and downs -- and am ever so pleased that today is up!

I sure hope that you can make it through this.

And on the self-serving side, I am sure glad that I lobbied you to use Caring Bridge. Your postings are a joy and an inspiration, not just to me, but, I am sure, to many others.

With best wishes for renewed health in the New Year.

Bob

*—Bob Hauser, December 20, 2018*

Good coffee Black

*—John Posner, December 20, 2018*

Good coffee Bl

*—John Posner, December 20, 2018*

Good coffee Black and strong Go for it. But wait for that colon infarction to heal! JJ

*—John Posner, December 20, 2018*

Dear Erik,

Wow, I miss a day of your Caring Bridge and everything can get turned upside down! I am glad to have read today before I read yesterday - glad that the numbers are moving in a positive direction and that you are feeling a bit better. Here's hoping all that continues.

Also, the idea of getting nourishment from the aroma of coffee resonates with me. Your description is so clear, I can almost smell the coffee myself.

I'll echo Bob and wish you renewed health in the year ahead.

Best,

Adam

*—Adam Gamoran, December 20, 2018*

## A New Strategy for these Blog Posts

*December 22, 2018*

I will dictate to Marcia relatively short medical updates, just so basic information gets to you in a timely manner.

Here is a quick update: this is a serious moment, struggling simultaneously on many fronts. For the first time, the doctor suggests that the outcome of this crisis is uncertain. Here are the issues:

1. spleen; the spleen enlargement continues and if anything is a little worse;
2. intestinal/colon infection with fever and constipation; constipation is aggravated by enlarged spleen inhibiting movement of intestine.
3. elevated sodium from trying to manage diabetes insipidus.
4. trying to deal with all this by having a few days taking nothing by mouth and restricting oral fluids to rest the gut, as well as IV antibiotics. Unbearably dry mouth and interruption of chemo temporarily.

Goal is to make it through this very rough period and get all these symptoms under control.

### Comments

Oh, my. What an unpredictable process this has all been, when I left on Thursday I was sure things were improving. Hope this turns around soon. Sending much love to you both!

*—Gay Seidman, December 22, 2018*

Thank you for taking the time to update. I have been thinking about you and praying for you. Please know how much you are cared about, both of you.

*—Pamela Oliver, December 22, 2018*

Sending love to you and Marcia as you struggle through this crisis. Hang in there.  
Bobbie

*—Barbara Marwell, December 22, 2018*



Thank you very much for the update. You are in our minds and hearts. Sending you tons of love to both of you!

—Valeria Galetto, December 22, 2018

Thinking of you both all the time and sending love.

—Kathy Cole-Kelly, December 22, 2018

Keep fighting Erik. I know you will. Thinking of you and Marcia and sending loads of love.

xxxxxxx

—Janeen Baxter, December 22, 2018

Hang in there, Erik. You are a tough cookie.

—elliott sober, December 22, 2018

What a rough time for you, Erik! And not easy to struggle along in this, Marcia! Thank you both for keeping us in the loop as we hold you both in our hearts.

—Myra Ferree, December 22, 2018

Dear Erik,

You have been a fighter all your life--hard at work to produce an intellectual foundation for building a better life for all. Keep fighting. We are all behind you and Marcia.

Love,

Mansoor

—Mansoor moaddel, December 22, 2018

Wishing you all the strength you need Erik! And Marcia!

—Harry Brighthouse, December 22, 2018

Thinking of you and sending so much love and care!

—Tom Malleson, December 22, 2018

Love you, Eriki and Marcia??

—Lisa Baker, December 22, 2018

Eric and Marcia, we add to all the good wishes and positive thoughts ,...may they help to sustain your

remarkable courage and strength.  
Carol and Peter

—*carol kitai, December 23, 2018*

sending all my love, support, gratitude and peace of mind. thinking of all the family, and of you, Erik, of course, especially as I am currently revising the last version of the RU essay on the corporation.

—*Isabelle F., December 23, 2018*

Erik and Marcia, I love you two very much.  
David

—*David Ja, December 23, 2018*

Erik, Marcia, les envío un gran abrazo y mucha fuerza.

—*Rodolfo Elbert, December 23, 2018*

Erik, sending love and strength, you are amazing. ??????????

—*SARAH S, December 23, 2018*

Your fortitude and perseverance are our goals, too! It is a super challenging time, but you have been defeating challenges in the course of your brilliant life and career - My heart goes to you, dear Erik! Sending you and Marcia all the love I have.

—*Masoud Movahed, December 23, 2018*

As Nazim said:

"Living is no laughing matter:  
you must live with great seriousness  
like a squirrel, for example—"

Or like you, Erik.

I sent you this poem earlier. I know you loved it. I keep going back to it every time I read your blog. Your will and happiness in the midst of all of this is an inspiration. Really. I send you and Marcia a hug each, and part of that poem, again... With love, ozlem

"Living is no laughing matter:  
you must live with great seriousness

like a squirrel, for example—"

I mean without looking for something beyond and above living,  
I mean living must be your whole occupation.  
Living is no laughing matter:  
you must take it seriously,  
so much so and to such a degree  
that, for example, your hands tied behind your back,  
your back to the wall,  
or else in a laboratory  
in your white coat and safety glasses,  
you can die for people—  
even for people whose faces you've never seen,  
even though you know living  
is the most real, the most beautiful thing.  
...

—Ozlem Altioek, December 23, 2018

Rik & Marcia,

When you come through this arduous struggle, you will have to co-author a book, perhaps using an old title:  
"To Hell And Back."  
Or perhaps you could use this opening line from from an old labor song: "Step by step, the longest march can be won, can be won."  
Of course any inspirational title will be suitable, because you are both truly inspirational.  
Best wishes and good vibes from the east coast.  
Love, Wally & Nancy

—Wally Rosenthal, December 23, 2018

Erik and Marcia,

I send love, and healing hopes, from the East Coast. I am envisioning my traveling wishes picking up volume and strength as they make their way to Wisconsin. I am so sorry that you are in this difficult and uncertain moment. I hope that the coming hours and days bring a turn-around. I wish peace and rest for both of you.  
Love, Janet

—Janet Gornick, December 24, 2018

Eriki and Marcia - From Mississippi I am thinking of you both and treasuring our recent time together. I love you both. Jenn

—Jennifer Wilgoeki, December 24, 2018

Dear Erik-- Just a note to wish you well during this hard period. With lots of admiration for your fortitude and

good cheer --Seana

—*Seana Shiffrin, December 24, 2018*

Eric--no one who has not experienced what you have can know what it's like. I hope knowing that so many people care about you and admire your struggle helps a little. Eve and John

—*Eve Silberman, December 24, 2018*

thoughts are with you, brother erik.

—*Joshua Cohen, December 26, 2018*

Thinking of you, Erik and Marcia, and sending you love.

—*Becca Krantz, December 26, 2018*

Dear Erik and Marcia- thinking of you, from afar (New Zealand), and sending much love.  
xox Julia

—*Julia Adams, December 26, 2018*

thinking of you in this difficult time

—*Matt Nichter, December 27, 2018*

My thoughts are with you. Stay strong.

—*Keedon Kwon, December 27, 2018*

## Time Horizon

*December 28, 2018*

I decided that it was time for me to get a better sense of where I stood with respect to the likely course of the disease. Various hints over the past week indicated that things weren't going so well, but it was all vague-- we were focused on the debilitating immediate symptoms: dry mouth, fatigue, fevers.

So, today I had this conversation with the HemOnc doctor: "I know it is pretty remote that I will survive this.

But what can I realistically expect? A few months? Six months? A year, maybe more than a year?"

"Six months would be a stretch", he said.

There you have it, from the HemOnc doctor on the floor. I will gather other views so there may be more variation. But I don't imagine the basic picture will change much.

In the coming days I am going to try organize the practical tasks ahead: clear out my office library with different destinations for different books (eg. My books and translations should be kept together); filing cabinets; journals (nearly complete NLR); artwork of various sorts; a lot of posters that we haven't used in the Havens Center, etc.

So, we have to find a destination for everything. I don't want to make any money off all the books in my library; that is, I don't want to have a book sale.

There are also filing cabinets filled with data from my 1980 study somewhere in the bowels of the social science building. All the original surveys. Unless somebody is tempted to do a follow-up study 50 years later, these probably should be trashed.

I'm listing these things just to alert my friends and colleagues that there is a lot of practical work to do.

I'm happy for many of the books to go to students who actually have libraries.

Anyone who is interested in helping with this should let me know. But we can figure out the practical logistics of all this later.

## Comments

Oh my gosh - that is heavy news. I think I have been not on that track. I love you, Erik - in part because of these wonderful journal entries, but also -- and of course in large part -- because of who and how you have been over the years. I won't go on about that now. Just: you are truly wonderful. Love, Jenny

*—jane mansbridge, December 28, 2018*

Erik,

I have been following your posts ever since I heard about your cancer several months ago. I had hoped along with everyone that your optimism and strength and wonderful treatment would win over the cancer. I am very sorry to hear about the latest prognosis. I will keep following your posts, listening, always listening... Jerry Himmelstein

*—Jerry Himmelstein, December 28, 2018*

It is impossible to read this without bursting into tears. You are loved so much, dear Erik, and will be forever for the light you shone on us. Sending you and Marcia all the love I have.

*—Masoud Movahed, December 28, 2018*

I was suspecting something bad when there were no posts for a while. But this frankly bloody awful. The power of your optimism is not invincible but the power of your love and the love everyone has for you is unstoppable.

—Myra Ferree, December 28, 2018

Eric  
My heart goes out to you and your family. You have always been an inspiration to me, that rare person with absolute intellectual integrity, boundless optimism, and a commitment to making this a better world. I am very glad for the time I have spent with you and grateful for all I have learned from you. I know that all of your friends are in your corner and hoping ...

—Debra Satz, December 28, 2018

Querido Erik, this is incredibly sad and heartbreaking. We love you so much. Pablo and Vale.

—Valeria Galetto, December 28, 2018

Rik,  
There really are no words that I can find to express my feelings when I read your latest message. Even my tears, my uncontrolled sobs are merely a physical expression. This much I can say, you have always been that mindful presence on my shoulder ever since our trip together in late August, 1963.

I'll try to communicate soon when I can better tell you what you probably already know is in my heart.  
Love,  
Wally

—Wally Rosenthal, December 28, 2018

Erik - this is devastating news. So hard to believe that you were here in Brisbane with us just a few short months ago before any of this was diagnosed. You have been such a wonderful mentor and friend and I have learned so much from you. Our first trip to Madison in 1987 to work with you was life changing. I'm thinking of you, Marcia and the family every day and hoping for a miracle.  
Hugs and much love  
Janeen xxxx

—Janeen Baxter, December 28, 2018

Can't find words. Sending so much love, to all of you.  
Gay

—Gay Seidman, December 28, 2018

Querido Erik, te mando un gran abrazo y mucha fuerza.

—Rodolfo Elbert, December 28, 2018

Dear Erik,

I am deeply saddened to read this entry. To me, you have always been not only a towering intellect but a remarkable human being as well--someone who inspires and energizes. Without doubt, you have been a grand source of emulation. My heart goes to you, Marcia, and the rest of your family. I am still hopeful--extraordinary things do happen.

With much love,

Mansoor

—Mansoor moaddel, December 28, 2018

Dear Erik,

I've been afraid this was coming, but just feel so terribly sad. You are such a mensch and such a wonderful colleague. You have done a lot for us in the past year alone. Yes, I can help with logistics about things in the office. I'll have more time in the spring term because I'll be teaching a half load. You don't need to worry. The big thing would be to tell us which things you want saved for specific others. We can handle the rest.

With love for you and Marcia and your family and all the people who care about you.

Pam

—Pamela Oliver, December 28, 2018

Dear Eriki! We were worried, like others, by the lack of news ... This post is so hard to read ... There's nothing we can think of to say right now, except that - we're here with Dan and Jen and we all send our love to you all.

—Mary Jo Maynes, December 28, 2018

I am praying for you Erik, like so many others for whom you've been a major influence either directly or through your writings. Just a couple of weeks ago, I was talking with my dad— a revolutionary socialist who spent several years behind the bars — about the importance of translating your books on real utopias into Turkish. There is so much more you can teach us all, and I like to think that many years from now you'll be telling your grandchildren how your doctor's grim prognosis turned out to be false.

—Kerem Morgul, December 28, 2018

Dear Erik,

I am so very sorry to read this, all best from me and Erica. I knew that the lack of news for the last days meant trouble, but it is still hard to fathom. Feels like yesterday you were here at our house. Hug Marcia from us.

—Stefan Svallfors, December 29, 2018



Oh, Erik. So deeply saddened to hear this. We are sending love to you and Marcia.

Matt and Ellen

—Matt Vidal, December 29, 2018

????

—Heather Crowley, December 29, 2018

We are devastated but, please, note that the doctor's prediction is pure astrology. Don't give up! Twice in her life Irene's doctors gave her a short period of time to live and she is still alive. The doctor may be wrong! Please, stay alive for the benefit of an immense community of friends and admirers.  
much love Boa and Irene

—Boaventura Santos, December 29, 2018

Rik,

I don't know Boa and Irene, but they are surely right. The doctors may be wrong. Your sister made it against all odds. Keep on keeping on.

Wally

—Wally Rosenthal, December 29, 2018

This is so hard. I spent the evening chatting with some you have such a huge influence on. And others who just feel you're what makes Wisconsin so great. So many of us are here for you, and you've built the kind of community where we are also here for each other. I hope you find some comfort in that. With love, Shamus

—Shamus Khan, December 29, 2018

Dear Erik - You have brought insight, understanding and warm heartedness to the discipline and so many of us within it. Your influence reverberates far beyond the rooms where you have taught, your students, colleagues, lectures, books, articles, studies, and letters. You have helped us think beyond the deeply rooted problems in societies--where our discipline too often stops-- to consider real solutions that would engender human flourishing. There is no time horizon for your ideas, or for your kindness. With much love, Margaret

—Margaret Vitullo, December 29, 2018

Dear Erik and Marcia, i wish so hard this was not a real entry. So much love, i.

—Isabelle F., December 29, 2018

Dear Erik, this is heartbreaking. It's hard to find words.

—Vivek Chibber, December 29, 2018

Dear Erik, heartbreaking is the right word. My mom and sister don't use internet well so I will say from me, my mom, my sister, we pass along all the strength and love the Kish women have to give. You, Marcia, all in the family will be in our thoughts and hearts. Andrea Kish

—Andrea Kish, December 29, 2018

I love you both deeply.

—Jennifer Wilgocki, December 29, 2018

Erik, Like everyone else reading this entry, I'm sure, I'm crying. Keep going, comrade, as long as you can. We won't forget you--until it's our turn to go. Thank you for everything, not the least being the intimate record you've shared with us. --David

—David Schweickart, December 29, 2018

Like others, I have nothing useful to say except to let you know that we're all thinking of you. (Well, that's not useful either, but I want you to know it). Tell us where you are going to be and when in the near future -- when visits might be welcome and where they'd be (and what state of health we should be in).

—Harry Brighthouse, December 29, 2018

Dear Erik - What you have been offering to everyone of us - including your journal entries - is something eternal. Much love to you and Marcia. I will keep praying for you.

—Cressida Lui, December 29, 2018

I will keep learning from you for as long as the disease permits you to teach us all how to live, how to think seriously, and how to enrich the lives of others.

—Dan Hausman, December 29, 2018

Dear Erik and Marcia

So very sad to read this. Sending back to you the love you have given to so many people for so many years.

—Kathy Blee, December 29, 2018

Dear Erik, I've learned so much from you over many years as colleagues, not just about how to be a scholar but about how to be a human being in what can be an impersonal environment. I will carry that with me. Sending

much love —Adam

—Adam Gamoran, December 30, 2018

Dear Erik,

I, like so many others, am crying as I read this, even though I am not surprised given that I've also been getting some news via my Aunt Ellen. Thank you for your honesty about it, for facing into your mortality directly, and helping all of us do so also. Though I share your optimistic temperament, I appreciate also turning to face the darkness.

I am happy to help with logistics though I imagine there are many others with closer ties to the contents of your library than me.

I don't think I would be in Madison if it weren't for you and Marcia, and I am deeply grateful to both of you for that and for your presence in my life and in the academic and non-academic communities we share. Please let me know if there is anything I can do to support you and your family .

Love,

Becca

—Becca Krantz, December 30, 2018

Erik, this is crushing to read. You've infected so much of my thinking about the world. I'll forever have a tiny, cartoon version of EOW hovering over my shoulder when I'm constructing an argument. We all completely adore you, sending love to you and Marcia.

Xo

David

—David Calnitsky, December 30, 2018

Sending along solidarity, but this is crushing news. Keep on keeping on, but if you have tasks that require assistance, I am more than happy to help. I am right down the street in Milwaukee and on sabbatical this coming semester.

All the best,

Mike McCarthy

—Mike McCarthy, December 30, 2018

Oh, Erik, I am so sad to read this.

We will find the best possible homes for your books, where they will be USED.

—Elizabeth Wrigley-Field, December 30, 2018

Erik, like Harry says, I have nothing useful to add. I am very sad and all of us, Paula, Aisha, Safina and myself - are sending our love to you at this moment. Please let me know when to visit. I'm coming to see you, boss!

—gianpaolo baiocchi, December 30, 2018

Sweet Erik, I love you. Warmly, Szonja

—Szonja Ivester, December 30, 2018

Dear Erik, My heart breaks reading this. Sending love and strength your way. Jennie

—Jennie Brand, December 30, 2018

Erik: We feel very sorry to hear this. Will always remember your teaching and passion! Love, Ricky and Jing

—Ricky Leung, December 30, 2018

Erik, I only saw this today but had heard you were in ill health earlier. I'm truly sorry to hear about how you're doing and only hope that your situation is more palatable knowing the hundreds of folks who care about you and the thousands whom you've had a profound effect on whether through your work or classes. I was only able to take one course with you but I still talk about it periodically and your Real Utopias project gives me hope about the future.

All the best!

—Josh Kissel, December 31, 2018

I'm really sorry to hear this, Erik, but as in so many things you continue to be an example to all of us. Keep fighting!

—jamie peck, December 31, 2018

Dear Erik,

I'm so sorry to read this news. I am always amazed at your capacity to write and share and organize, no matter what the obstacles. You continue to be an inspiration and I'm so grateful for all you have given to so many of us.

—Stephanie Luce, December 31, 2018

Dear Erik, This is horribly sad. I am so thankful to have had some years as your colleague and remember your kindness and good advice. I hope you have as many good days as possible ahead. Laurie

---

—Laurie Edelman, December 31, 2018

Heartbroken. Thank you for all your years of scholarship, mentorship, and warmth.

—Alex Hanna, December 31, 2018

Dear Erik,

I remember when I was in graduate school at Berkeley hearing other talk in warm, glowing terms of how Erik Olin Wright brought people together and created intellectual community. I also witnessed this quality first-hand when we overlapped as presidents at ASA.

It is with a heavy heart that I read this news. As the posts show, you have touched the lives of many of us, and, of course, countless readers beyond. This news from the HemoOnc must be difficult to absorb. I hope that you have many good days ahead where you feel relatively well.

I will be keeping you in my thoughts and prayers.

Warmly,

Annette

—Annette L., December 31, 2018

I would not be back in the Midwest, if it wasn't for you Erik. Like others, I have been greatly influenced by your work, particularly Real Utopias. I still remember how floored I was when you emailed me back, the first time I reached out to you. A few days after that, I remember cutting vegetables in my kitchen, thinking "Damn, Erik Wright emailed me back." While I obviously would have loved to study with you, I appreciate what I have learned from this blog and what I will always have in your books on my shelf. I am in Madison and more than happy to assist in whatever needs to be done. Much love.

—Adam Szetela, January 2, 2019

Erik, I am late to reply but am so sorry to hear this, it has always been a pleasure to wrangle technology with you. Please know I (and my colleagues) will do our utmost to ensure your digital life is preserved (or not) in whatever ways you wish, you have only to ask. Best, and as many good days as possible, to you and your family.

—Caitlin Tefft, January 7, 2019

**nothing much to report**

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*December 31, 2018*

I am dictating this to Marcia because I am finding it extremely hard to write, extremely hard to keep my eyes open and therefore to write. The past two days, I have mostly spent in bed, sleeping. And I haven't had a chance to follow up with other doctors yet about the "six month stretch" comment in my previous blog post. I am feeling a bit more optimistic, as many people in your wonderful comments have reminded me of the difficulties of reasonable statistical estimates and the many experiences people have had of being told they had little time left and then living a long time after. So I will get back to the business of living and leave the business of dying to the doctors.

## Comments

Will send an email Erik, BIG HUGS, Joan and Kjell

*—Joan Fujimura, December 31, 2018*

You are a wise man, Erik! Rest as much as you need and think positive thoughts. As a good friend of my father's recently told me, "I understand that people die. But since I have only experienced life, there is no empirical evidence that I will die." It is that simple.

*—Szonja Ivester, December 31, 2018*

The world needs you and your wisdom,so what can I say except: Best Wishes for 2019.

*—Lennart Olsson, December 31, 2018*

Erik, Marcia, I just sent an email about alternative therapies to Erik's department address. Hugs, Joan

*—Joan Fujimura, December 31, 2018*

We hope that 2019 is the year that you beat rhe odds. Love from us and our children. Carol. and Peter

*—Peter Rosenthal, December 31, 2018*

Glad to hear this, Erik. Norma and I are thinking of you and Marsha.

*—elliott sober, December 31, 2018*

Ciao, erik. In fact, when you told us about the 'six months is a strech' statement by your doctor, I remembered when my father was told the same, 15 years before he died. I really hope te same will happen to you. Un abbraccio d

—Donatella Della Porta, December 31, 2018

Beautiful, exactly beautiful, Eric. I hope you and Marcia have a wonderful night.

—Susan O, December 31, 2018

You cannot imagine how much this post lightened my heart, dear Erik! Sending you and Marcia all the love I have.

—Masoud Movahed, December 31, 2018

Dear Erik,

This is more like it. As I see it, your bone marrow transplant was successful. All we need to do is to persist another month or so for the new white cells to get ready to fight the rogue ones effectively. Let's think positive and do all we need to do to make this happen. As Zarathustra says "positive thoughts, positive words, and positive deeds."

Happy New Year to You Marcia

Love,

Mansoor

—Mansoor moaddel, December 31, 2018

Excellent!

—Sarah Siskind, December 31, 2018

Dear Erik, Happy New Year's Eve to you and Marcia. We are holding you in our hearts and wishing you only good things.

Love, Cindy

—Cindy Costello, December 31, 2018

That's the best sentence at the end of your post!!! It's brilliant and needs to be a bumper sticker !!! I love you both so much and thinking only positive thoughts for you. So much love to you and Marcia!!!!

—Kathy Cole-Kelly, December 31, 2018

Happy new year, dear Erik and Marcia. May the new year bring you all that is good!

Love,

Sonia

—Sonia Baku, January 1, 2019



Erik - Happy New Year! May 2019 and beyond be filled with pleasant news, happiness and love for you both.

—Cressida Lui, January 1, 2019

Happy new Year, Erik and Marcia! Lots of love & positive energy from AJ, Yeonhee, and me!

—Chaeyoon Lim, January 1, 2019

Sleeping is good. It will give your body a good rest so it can heal itself. Very soon, you will start to regret giving away your books!

—Vicky Chang, January 1, 2019

Dear Erik, I was deeply saddened to read your December 28th journal entry, but I was heartened by the more optimistic note in this entry.

Anya and I are leaving the country tomorrow for a two-week trip abroad, but we plan to visit you (if you're up for it) after we return to Madison. For now, please know that you're in our thoughts and (for me at least) prayers.

I also want to say that for the past 18 years you have been a wonderful mentor, colleague, and friend. I have learned so much from you over the years. More, I'm sure, than you realize. Not just academically or intellectually. Most importantly, you are an incredible role model as a colleague: thoughtful, humane, generous, deeply caring, always looking for the best and looking to bring out the best in others. I think my New Year's resolution will be to try to emulate that spirit as best I can.

May the love and support of your family and friends bring you strength and health in this new year.

—Chad Goldberg, January 1, 2019

## HAPPY NEW YEAR 2019

January 1, 2019



the optimism lurking in 2019.

## Photos





## Comments

Happy new year to all of you! And much love.

—Gay Seidman, January 1, 2019

Happy New Year to you all.

—Joshua Cohen, January 1, 2019

Optimism looks great on you, professor! Wish you a happy new year with your lovely family.

—Kerem Morgul, January 1, 2019

Happy and Inspiring 2019 to all of you! These photos are so beautiful - sending you all the love I have!

—Masoud Movahed, January 1, 2019

Happy new year to you all.

—*Keedon Kwon, January 1, 2019*

How wonderful to see you all celebrating together! Happy New Year!

—*Mary Jo Maynes, January 1, 2019*

Thanks for sharing your New Year's celebration - a treat to see you all! Big hugs and all best wishes...

—*Cathy Loeb, January 1, 2019*

Wonderful Erik and Family,

These pictures put a smile on my face.

Like you, I also spent NYE on the HemOnc floor . Also like you, we are ready to face the new year with renewed energy.

One day at a time.

Hugs!

—*Szonja Ivester, January 1, 2019*

Happy New Year to the family that brings such joy. Love and hugs. Bobbie

—*Barbara Marwell, January 1, 2019*

Happy new Year and much love from the left coast crew-- Martin and Mona and Ben and Juliana and Max and more...

—*Martin Goldstein, January 1, 2019*

Happy New Year. Great pictures.

—*Pamela Oliver, January 1, 2019*

Happy New Year Professor!

—*Joshua McAuliffe, January 1, 2019*

Rik, Marcia, Jenny, & Becky,

The nearness of three generations of close family is surely a wonderful tonic. And silly photos don't hurt. May that and your sober optimism carry you forward.

Much love,  
Wally

—Wally Rosenthal, January 1, 2019

These lovely photos boosted my energy, made me smile, and filled my heart with joy. What a wonderful way to end the first day of the new year.

Many thanks for sharing.  
Happy new year Erik, Marcia, and the rest of the family.  
Love,  
Mansoor

—Mansoor moaddel, January 1, 2019

You have a wonderful smile Erik. And in the top picture you do a wonderful imitation of Elton John! Keep up the good work and keep smiling.

—Dan Brakarsh, January 1, 2019

Dear Erik,  
These photos are a gorgeous, spirit-raising, gift to all who care about you.  
May 2019 bring mountains of reasons for optimism.  
Happy New Year to you and your beautiful family.  
xxxx Janet

—Janet Gornick, January 1, 2019

Dear Erik,

Thank you for posting these joyful photos, and sharing your feelings and thoughts even when you are exhausted. It's a great gift to know what your life is like and hear your "voice" in everything you write. I am glad to still feel close even though I have not seen you in years. You were very kind and supportive to me in Madison and helped restore my confidence by telling me I was resilient. However, the joy, humor and empathy in your post have shown what true resilience looks like. I hope you will continue to find joy and meaning each day in 2019 and well beyond.

Sending you a big hug from Seattle, and warm wishes to you, Marcia, your family and devoted friends for a new year full of love and kindness,  
Aimée

—Aimee Dechter, January 1, 2019

Beautiful photos. Happy New Year to you all from your friends “down under”.  
Much love xxxx

—Janeen Baxter, January 1, 2019

To you too! And all of you!

—Sarah Siskind, January 1, 2019

So glad to see you surrounded by your fam and seeing you sitting up!!!! Sending love!!!

—Kathy Cole-Kelly, January 1, 2019

And so good to see Jenny and Becky!!!

—Kathy Cole-Kelly, January 1, 2019

I am your former student from Hong Kong. Just want to say you are a great teacher and a much respected scholar.

—Alex Chan, January 1, 2019

Happy New Year, Erik! These pics made me laugh out loud, startling the people nearest me. Keep propagating joy!

—Ben Manski, January 1, 2019

Great pictures, Erik!

—elliott sober, January 2, 2019

## FOG NUMBERS

from Carl Sandburg's Honey and Salt

Birth is the starting point of passion.  
Passion is the beginning of death.  
How can you turn back from birth?  
How can you say no to passion?  
How can you bid death hold off?  
And if thoughts come and hold you  
And if dreams step in and shake your bones  
What can you do but take them and make them  
\_\_\_\_\_ more of your own?



\_\_\_\_\_ Of course, a nickel is a nickel,  
 \_\_\_\_\_ and a dime is a dime--sure--  
 \_\_\_\_\_ we learned that--  
 \_\_\_\_\_ why mention it now?  
 \_\_\_\_\_ of course, steel is steel;  
 \_\_\_\_\_ and a hammer is a hammer;  
 And a thought, a dream, is more than a name,  
 \_\_\_\_\_ a number, a fixed point.

Walk in a midnight fog now and say to it: Tell  
 \_\_\_\_\_ me your number and I'll tell mine.  
 Salute one morning sun falling on a river ribbon  
 \_\_\_\_\_ of mist and tell it: My number is such-and-  
 \_\_\_\_\_ such--what's yours?

Of what is fog the starting point?  
 Of what is the red sun the beginning?  
 Long ago--as now--little men and women knew in  
 \_\_\_\_\_ their bones the singing and the aching of  
 \_\_\_\_\_ these stumbling questions.

—Nancy Folbre, January 2, 2019

Hi Erik, happy new year to all of you! Everyone in the academic community here in Argentina wishes you the best. I was at a meeting of the class analysis community recently and all professors and students have the greatest memories of your visit. Everyone asked me to tell you that you are much loved here and we expect that you will get better and come back for your 4th visit here. I promise to organize a visit to Ushuaia, which you wanted to visit your previous time here to give the farthest south real utopias lecture in record! Abrazo.

—Rodolfo Elbert, January 2, 2019

love these photos!

happy \*shmoo\* year, little ones!

—Matt Nichter, January 2, 2019

Happy new year from Scotland, and here's to optimism!

—Tod Van Gunten, January 3, 2019

I just learned of your situation from Jennie Brand. Your strong spirit and deep humanity show through in your comments, another chapter in your contribution to the world.

—William Roy, January 3, 2019

Hello, Erik! Thank you for sharing the lovely photos of you and your family. It's good to see a grin on your face along with the silly 2019 glasses. I think of you often -- not as a scholar and teacher, as many do, but as a fiddle player. I have a fond memory of you playing your fiddle at a gathering at your house several years ago. I hope you're listening to music now, as it can bring great joy. I send warm wishes for courage and a calm heart.  
Charlotte

—Charlotte Frasca, January 4, 2019

## Grim update

January 4, 2019

I can now give more definitive news about my medical situation. According to the latest indicators, I have three or four weeks left to live. There may be surprises of course, this happens. And I continue to make use of whatever chemo is left to fight the AML, but the fact of the matter is we have run out of options. And the doctors feel there are something like three or four weeks left.

This means I've shifted into a different mode of operation. I told the doctors that my priorities are unequivocally to maximize the amount of energy I have, to be able to write, and enjoy my family in these last days. But I do plan to write if I have the energy to do so. I'm happy to have visitors. But I can't plan and coordinate them. So I'm telling people to just come by for a short visit, even if there's overlaps with other people. I suppose the one nice thing about this dreadful news is that I can drop the food restrictions that are concerned with food borne illnesses. We're thus having a sushi banquet tonight. If my taste buds don't cooperate, I'll kill them!

Looking forward, I will continue the blog, but it will be a bit more intermittent, since I have other writing priorities that are more important. In particular, the letter to my grandchildren. If any significant change in my condition occurs, of course I will do a blog post on that.

Love,  
Erik

## Comments

Bless you Erik, along with Marcia, and your wonderful sharing and posts and zen approach to severe illness.

We are realists but Joan and I focus on "There may be surprises."

—*doug maynard, January 4, 2019*

Oh Erik, I am so very, very sad to hear this update.

For now I am rooting for your taste buds at the sushi feast tonight.

You are so much in my thoughts.

—*Elizabeth Wrigley-Field, January 4, 2019*

Erik: I am sorry to have this news. Wish I was there now to give you a big embrace.

Love to all, Josh

—*Joshua Cohen, January 4, 2019*

I may change the plans and come

—*Magali Larson, January 4, 2019*

Very sorry to hear that, but docs don't know everything - I pray for surprises of a good sort for you. And that, along with dropping food restrictions, the docs let you come home. Nice as the hospital has been to you, there is much to be said for the comforts of home and the surprises that come from that. Sending love and wishes for many good surprises still.

—*Myra Ferree, January 4, 2019*

Erik -

I'll never forget how supportive you were of me as a grad student, always, no matter what. I've said many times to others what I should have said at least once to you, "I've always known Erik to do the right thing. Even if he was frustrated personally it never got in the way of his doing right by others." You did that for me as I went on the market, and you did it for so many others. I've tried to play it all forward with my students. Including, as I've told you, my own advisee dinners modeled on your own. You have a monumental intellectual legacy. But it does not eclipse, to my mind, the personal one. You've served as a model for me of what it means to be a good advisor and person. And one I'm thankful for.

With all my love,

Shamus

—Shamus Khan, January 4, 2019

Erik, I'm so sorry to hear this horrid news. I hope that you do indeed have surprises and that you have the energy to write and do and eat what you like. Sending warm thoughts from California. Laurie

—Laurie Edelman, January 4, 2019

That's one incisive kick in the gut. Love to you an Marcia and the girls and the little kids. Will see you soon.

—Sarah Siskind, January 4, 2019

Erik --

I am so sorry to hear this grim report. I have been following your blog -- if I may call it that -- avidly and hoping for the best. Your take on the illness, treatment, and consequences has been informative and inspirational. I trust that you will make good use of your remaining time with us. It is a rare pleasure to know you.

Peace and love,

Bob

—Robert Hauser, January 4, 2019

Erik, I will be thinking of you and sending you love and peace. I feel so much gratitude for the innumerable ways you have graced the world with your presence.

—Jennie Brand, January 4, 2019

Death Erik, this is such a difficult blog entry to go through. All my love to you and Marcia, and your daughters and grand children, and family. Will travel to the US mid January and will manage to come to see you.

—Isabelle F., January 4, 2019

Oh, Erik, I'm so very sad to read your news but will hope for the surprises you mention. In the meantime, bon appetite -- may this evening's banquet be delicious! I send warm wishes for energy and serenity, and I hope you'll enjoy writing -- and reading -- the letter to your grandchildren.

—Charlotte Frasca, January 4, 2019

Hi Erik,

I am thinking of you and keeping you and your family in my heart and thoughts these next few weeks (and longer!). Like others, I am crossing my fingers for the surprises you mention. I hope you know how profoundly

you have touched so many of us, whether in person or through your writing, and I am grateful to have had the opportunity to know you.

With love and warm, positive energy,  
Aliza

*—Aliza Luft, January 4, 2019*

Thinking of you all with much love and sadness, and wishing you great joy in your remaining time.

*—Becca Krantz, January 4, 2019*

Dear Erik,

You are in my thoughts. I am hoping for the best, wishing for pleasant surprises and positive development. With much love.

Mansoor

*—Mansoor moaddel, January 4, 2019*

Erik, This is terrible news. Sending you love --and gratitude for all you have done and who you are.  
Debra

*—Debra Satz, January 4, 2019*

Dear Erik,

I was so sorry not to see you when I was at the Havens Center in early December. The Center itself, along with your writings, the students you have mentored, and your loving family, are all great testimony to the wonderful work you have done for such a long time. By a strange fate, my partner and I were at a lodge in northern Ontario in July (we were taking our son to a baseball tournament) when we encountered a left-wing couple from New York. In the course of discussion we discovered that he was a retired NYC postal worker -- and your cousin! We had a lovely chat and I passed on my regards to you. Now I want to send solidarity, friendship, and good vibes for the writing you plan to do, as well as the precious time you are sharing with your family.

With great admiration and respect,

David McNally

*—David McNally, January 4, 2019*

You are an amazing and inspiring man, Erik. I've always thought so. Your and Marcia's love, courage and support for one another, your whole family's in fact, through such adversity, is beautiful. Much love, Julia

*—Julia Adams, January 4, 2019*

My dear Erik, I'm sending you loads of love. I know that you are surrounded by it already, but it never hurts to have more. Sushi banquet sounds perfect. Hugs and kisses to you.

—*Szonja Ivester, January 4, 2019*

You and Marcia were spoken of with such love last night at the Feminar, Eric - the Feminar another of your legacies.

We continue to be inspired by who you two are together. We send your generations of family our love.

—*Susan O, January 4, 2019*

Dearest Erik:

With tears in my eyes and deep sorrow in my heart, I want to thank you for offering your unstinting support of all sorts to me as your student and advisee. I still remember, back in early 2011, how inspiring it was for me to learn about your Real Utopias Projects, your vision and commitment to draw up designs and blueprints for institutions necessary for a just social order, since they are not guaranteed by history. This news is so crushing, but I remain hopeful for great surprises to happen. You are loved so much and will be forever, for the light you shone on us and the wonderful soul that you are.

Sending you and Marcia all the love I have - and very much looking forward to seeing you both very soon.

Yours,  
Masoud

—*Masoud Movahed, January 4, 2019*

Erik—you are truly an inspiration, deeply admirable in your stoicism. Your important work will live forever, but I think so will your kindness and warmth. I think back to how kind you were to me as a prospective student—you were both the most prominent person I wrote to and easily the nicest one, and I'm not just saying that—and feel eternally grateful. Thanks for everything. I'll drop by soon.

—*Griffin McCarthy-Bur, January 4, 2019*

Dear Erik,

Rob and I treasure our time as your colleagues in Madison. You have continued to make our world and the World a better place in the years since then, for which we are very grateful. We wish you peace and comfort and send our love. We are keeping you and Marcia and the rest of your family in our hearts.

Judy

—*Judith Seltzer, January 4, 2019*

Dear Erik and Marcia. We are so sorry to hear this terrible news. I hope you know how important you are to us.

Going to Madison to work with you changed my life and getting to know you and Marcia was an immense privilege. We wish you all the very best at this time. With love, Janeen, Mark, Jessica and Kate.

—Mark Western, January 4, 2019

Dear Erik, I'm so sorry to hear this. As you know from our recent talk when I came to visit you in Milwaukee, my short time with you in Madison was formative to my thinking, and I will never forget your kindness and generosity as an intellectual and as a person. I will keep you and Marcia in my thoughts and wish you strength.

—Barry Eidlin, January 4, 2019

Much love to you and all the family, Eriki. It's so hard to find anything else to say right now. I keep writing things and deleting them because words feel inadequate. Makes me appreciate your blogging all the more. We are thinking about you, MJ and Ron

—Mary Jo Maynes, January 4, 2019

Dear Erik - I am so overcome with emotions, I really don't know what to say. ... Regardless of what lies ahead, I wish you joy and love. You will continue to be in my prayers. Warmest hugs to you, and to Marcia.

—Cressida Lui, January 4, 2019

I am so saddened by this news. Those were such formative years for us all (1988 batch) and you were always a brilliant and consistent support for our intellectual development. In many ways you will always continue to be alive for us. I am stunned by the beauty of your bravery at this stage of your life. I sense the peace. Be well. I will light a candle for you here in Lahore, Pakistan

—sara abraham, January 5, 2019

My precious friend, I thought that I had got the most of you through your books which have accompanied me since my early youth (and I was really very happy when, some years ago, you accepted to deliver the Annual Nicos Poulantzas Lecture and also speak in a public event). The way you are facing this critical phase of your life has proved me wrong. I still learn from you. I would like you to know that the Greek edition of "Real Utopias, translated by Loudovicos and Elena, is now available in the bookstores and I am sure that Marxist scholars, students and activists in my country will benefit from its insights. Dear Erik, mine and Kalliope's (your guide in Athens) thoughts are with you.

—Haris Golemis, January 5, 2019

Erik, I will always cherish the time I had in Madison and your intellectual generosity. I wish you, Marcia and the whole family great peace and love. Steve

—Steve Viscelli, January 5, 2019



Dear Erik, I am very sad to read that, and I admire the courage of your words. I keep in mind our great discussion in a bar in Paris almost fifteen years ago. It was very inspiring to me and it will be a great memory.  
Yours  
Fabien, France

*—Fabien Tarrit, January 5, 2019*

Erik, we have never met or spoken but your work has had a great impact upon me, my writing and activism. I know without doubt that I am not alone. I hope it brings some warmth to be in the knowledge that your actions in this life have spread their influence through so many people, and will continue to ripple into the future, long beyond the next four weeks

All the best, and thank you

Graham x

*—Graham Jones, January 5, 2019*

Dear Erik,

This is devastating. I am glad you are opting to focus on maximizing your energy to enjoy family and write. I hope your taste buds cooperate!

Everyone who knows you understands that your many and broad contributions as an academic, activist, teacher and mentor will be long-lasting. Personally, as my PhD advisor, your contribution to my intellectual and personal development was deep and profound. You were an ideal advisor – intensely engaged, generous with your time and advice, insistent and demanding but always fair and kind. I try to model my own advising and mentoring on your example.

I wish I could come see you in Milwaukee but alas I cannot make it. I cherish the times we got to spend together in recent years when you travelled to London, in addition to our years of close interaction during grad school.

I too am hoping that the doctors will be wrong. And am sending warm thoughts and vibes to you. I will always remember you fondly, my friend.

Love,  
Matt

*—Matt Vidal, January 5, 2019*

Dear Erik, Vish and I are so very sad to hear this news. We've read your blog consistently and have been touched and inspired. It's hard to find words to describe our feelings--you're in our thoughts constantly. We have enjoyed our journey with you to find pathways to the cooperative economy over the last six years,

taking us to many interesting places around the world. We've also loved the many amazing meals you've cooked us. Everywhere we go, we find the imprint of your work. It's an inspiration and compass for many people, including us in South Africa. You will continue to guide us for many, many years. We send you, Marcia and your family much love and strength. Love, Michelle and Vish

—Michelle Williams, January 5, 2019

Dear, dear Erik:

I will treasure the dinner at your place last year even more. It was a lovely evening on every level, a few days before the horror struck. Your intellectual work and your comradeship have been extremely important for many more people than you realise and all of us at Verso and NLR greatly value your contributions to both outfits. We're all on the runway but you're taking off far too soon.

a warm embrace,

Tariq

—Tariq Ali, January 5, 2019

Eric, my friend, my old neighbor,

We are sending love from the mandels and diamonds to you and Marcia and the family and holding your glowing smile in our hearts.

—cherie diamond, January 5, 2019

Dear Erik, I am so sorry to hear this news. I owe you so much both academically and personally. I still remember how much support you gave me when I was trying to get a professor position in the US about ten years ago and when my wife had a kidney failure that eventually required dialysis and then transplantation (her kidney is still functioning well). Your support made it possible for me to overcome those difficult times. I deeply regret that I can't do anything to return the favor. I also regret that I did not have more time with you when you visited South Korea a few years ago. You were a wonderful teacher and good man to me. I cannot thank you enough for that. The older I get, the more I have come to realize how generous you were to me. I will always remember you fondly.

—Keedon Kwon, January 5, 2019

Dearest Erik: it is with profound sadness that I read your “grim news” posting. Although I have known you and Marcia for all the years you have been in Madison, it was not until after Jerry died that I had the good fortune to develop my own relationship with you. My admiration and respect for you only deepened over the last summer when I did get to spend time with you, and through reading your extraordinarily courageous and self-revelatory postings on the Caring Bridge.

I have kept the history of your political development to share with my youngest grandchild, when he is old enough to appreciate the serious thought that goes into the development of a political self. Many of us have memories of childhood “run away” adventures, but your recounting of your story is one of the most charming and humorous that I have read.

I wish you energy to write more of your memoirs. However much you complete will be a treasure for your grandchildren and anyone else who is privileged to read them.

Jerry always said that whenever Erik reads a file, his interpretation always increases the quality of the work.

Your ability to find optimism even in the darkest of times marks you as a real Utopian.

My love for all you are and have given to those privileged to know you.

Bobbie

*—Barbara Marwell, January 5, 2019*

Dear Erik,

Thank you and love. I have no other words.

Philip

*—Philip N. Cohen, January 5, 2019*

We, too, have been following your blog with a sorrowful heart. What a valiant effort this has been for all of you. The images of those beautiful grandchildren ringing in a New Year and of Erik surrounded by his three favorite women depict the legacy of a life well and fully lived. We wish you all the strength in the world as you navigate this next challenge.

Wendy and Jim House

*—wendy fisher-house, January 5, 2019*

Enjoy that sushi banquet, Erik. Anya and I are thinking of you tonight in Tel Aviv. We may be far away at the moment, but you are in our hearts.

*—Chad Goldberg, January 5, 2019*

Erik, I am so sorry to learn this grim news. You were a good friend to me during my years in Madison. Then and since you have shown me and many others how to be a mentor and how to do committed scholarship. My thoughts and love are with you, Marcia, and your children and grandchildren. Richard

*—Richard Lachmann, January 5, 2019*

Dear Erik, I will never forget your support and encouragement to me even as a grad school applicant, and I am forever indebted for your kindness. I remember feeling so surprised that a scholar of your calibre would take time to talk to a prospective student. You inspire generations of scholars and have left your mark in many hearts as the nicest person we have ever come across. Thank you, truly, for showing us how life should and can be lived.

*—Sherry Chan, January 5, 2019*

My dear Eric,

It was a shock to hear what you are going through. I am keeping my finger crossed. Keep fighting. I know of cases where your illness has been cured. Why not you. Remembering your most successful visit to Prague in 2005. With warmest greetings Tibor

*—Tibor Vasko, January 5, 2019*

All the blessings of this Earth to you, Erik. I wish I could see you one more time and offer a heartfelt embrace. I can tell you that our book is soon going to press. You have helped elevate one more good idea, after a lifetime of conceiving and sharing fresh insights. May you find peace and know that you are loved, both by those at your side these next few weeks and by hundreds more who can't be with you. --John

*—John Gastil, January 5, 2019*

Hi Erik, I wish I had knew this channel earlier to connect with you for a visit. I got it yesterday from one of the classmate. I often thought of your intellectual with humor when passing the Sewell. It is a complex feeling when reading this message since I had a slight hope to join more spring camps someday. SOC621 was my first sociology class and I felt deeply lucky to have you as the mentor. Perhaps the gain for me is not only empirical Marxism theories but the music, the talks, the laughs, the critics of essays and the wisdom of facing life left by you. Wish you peaceful and enjoyable days wherever they are.

*—Ellie YANG, January 5, 2019*

Hi Erik - I'm really saddened by this shocking news. You've achieved so much and we've been looking forward to more. My thoughts are with you and your family. All the best, Alex

*—Alex Callinicos, January 5, 2019*

Oh Erik, I had heard you were sick but just learned now that things are serious enough to merit a Caring Bridge. I am glad you are writing when you can and look forward to reading your thoughts. For now, I just want to tell you that you made a big difference in my life. Your support for my work -- and me!--made it possible for this girl from the working class to become the first in her extended family to earn a Ph.D. Your writing has inspired lots of imagination about possibilities for larger scale social change. However, your mentoring and support and the communities you have built around the project of change have helped me (and I suspect many others) surmount the very concrete barriers of social class in our own biographies. I hope that my writing and teaching have "paid it forward" on my debt to you. I wish you and Marcia, your daughters and grandchildren, the best possible lives together during this time. Hugs and love.

*—Joey Sprague, January 5, 2019*

Sending you love, admiration, and more love. (I am a fan from afar).

*—Sherene Seikaly, January 5, 2019*

Dearest Erik,

You have fans around the world and I've long been an enthusiastic one. I'm soon meeting up with Rob Mayer (another of your fans) who alerted me to your current situation. So I just wanted to take this chance to tell you that to me, you've always represented the ultimate best in sociology and idealism-in-practice-- including figuring out what kind of happiness or sense of well-being to celebrate ( I loved your blog on that!) . So please know that I'm thinking of you and greet you, and wish you comfort and well-being and send you lots and lots of love,

Arlie Hochschild

*—Arlie Hochschild, January 5, 2019*

Dear Erik,

Throughout my life, I have been influenced by many thinkers but very few people have inspired me both by their intellectual capacities and their personality. For me, you are not only a sharp mind but also a living example of humanity. It is somehow comforting. One of those lights when our times seem dark.

We have not met for more than one year. I followed your journey with cancer through your blog posts. I admired your strength and your mental clarity. You were not afraid to share your deepest questionings and show your vulnerability. Thank you for that.

All of this seems somehow unreal. I am far away and I won't be able to come and see you. When I close my eyes, the illness has gone. I see you playing violin. My toddler is dancing with your students. We all have so much fun, we cannot stop laughing. I hear your voice in the office next door singing joyfully for your grandchildren. As a man who never lost his inner child, you have special connections with kids. I listen to your passionate explanations of the Wisconsin Capitol occupation. Time flies. I imagine you riding your bike in the city, cross-country skiing around in the winter or reading a book in your family house by the lake. I can still connect to the silence we shared in all those moments of meditation before the beginning of your lecture.

You are alive within me, Erik. I feel so grateful that our paths crossed. Dying is not a failure. One day or another, we will all meet death. Suddenly or slowly. Until then, we live. We live and we love. So now I just want to send our loving thoughts from the other side of the ocean, for you and Marcia as well as your daughters and grandchildren.

Love, Coline (Nina, Anouk & Paul are joining me for the hugs)

*—Coline Ruwet, January 5, 2019*

Dear Erik,

I'm been following this site closely ever since you started it, but never posted a comment before because - as you know - I often get self-conscious about finding the appropriate words to say in this kind of situations. Sorry

about that. But I've always been encouraged and heartened by the optimism and wisdom in each and every of your posts. I truly believed that everything would be okay when you had the transplant, and was so ready to welcome you back in the near future. Even with all the following complications, I didn't think for one second that this would be coming. I am shocked and extremely saddened by this, but I pray to all supreme forces, all gods that I could name, that the doctors are wrong and we will be sitting together and talking about this wild ride of your life many years from now.

I'm not sure I can adequately express my gratitude to you, for teaching me so much, not only about sociology but also about life, for always supporting me and my premature ideas, and for always being a role model of an intelligent, meticulous, remarkable scholar, and a kind, caring, selfless person. Every minute I got to spend with you, everything I heard you say and saw you do inspires me and reminds me of what I wish to grow up to be. I always feel proud to be able to say that I've taken classes from Professor Erik Wright, have talked to him in depth, have shown him my work, etc. I feel truly, truly lucky to have known you and learned from you. It will never be the same without you, knowing that I couldn't ask for advice from the wisest mind I've ever known. But I will - as will all of us who have had the fortune to be your students, I'm sure - continue to hold myself to your standards, for academic work and for life in general, and always strive to make you proud! Hope you enjoy spending time with your wonderful family and writing and eating all the food you want!

With all the love I have and the best best wishes,  
Siying

—Siying Fu, January 5, 2019

Dear Erik;

Very sad to hear this; I just learned about your condition. From the early days of the Class Structure and Class Consciousness project, and later, as when you visited us here in Oslo, I have always been very impressed by your work. Your capacity for engaging in intellectual discussions with your own previous work shows an admirable openness that the rest of us should aim for. You are an academic who knows that also when you think you've got it just right, there's always a new question to answer. Or, find a new way to think about an old question. Take care; I'm sending lots of love; Gunn Elisabeth

—Gunn Birkelund, January 5, 2019

Dear Eriki,

I am so saddened, really gutted, to hear this news. Your blog has been such a beautiful way for me to get to know you and connect with you as an adult. I wish it had not come from these circumstances, but I sincerely thank you for this chance.

The Eriki I knew was a part of my childhood. Your house was a place of comfort and warmth for me and I will never forget the many Thanksgiving evenings where we wheeled a turkey over in a red wagon and then had a feast with the many people from all over the world who found themselves at your home for the holiday. The most special part of the memory for me is you and Becky playing fiddle and all of us doing the Virginia Reel. I can almost taste the ecstatic feeling of sashaying all the way down the line under the tent of a million arms with

Jenny!

One other funny memory that came to me as I was writing about the Virginia Reel was a magic show that Becky, Jenny and I put on for you guys at our house - I remember that we were wearing unitards and that we made bad puns as hints for one another. Thinking about it now as a parent of a future magic show maker, it must have been fun to have dinner and then follow it up by a performance of hilarious but totally unimpressive magic by your children who have spent the whole evening preparing said performance!

I wish you enough energy in these last days to carry on your writing and to relish in your beautiful family and mostly I hope you are taking in all the love you clearly have cultivated in this lifetime. It's pouring through the your writing and the comments in your blog.

I love your whole family and am sending my love to all of you as you navigate this difficult transition.

Amelie

*—Amelie Davidson, January 5, 2019*

Much love and appreciation Erik! I have never met you, but as a sociologist I have always been very influenced by your work. Thank you for all you have given us! We will have a drink for you tonight in Beirut :)

*—Rima Majed, January 5, 2019*

Dear Erik,

I am so sad to hear this news. The last time I checked in several weeks ago post transplant things seemed to be going well and I was looking forward to having you back on the P&S board. I have so enjoyed working with you and learning from you and arguing with you over the past many years. You have been so brave through your illness. love, Molly

*—Molly Nolan, January 5, 2019*

Oh Erik, I wish I could be near you at this time. Hug you and tell you (again) about how much you taught me about LIFE. I just hope doctors are wrong and you can turn this into one of the beautiful stories you tell in conferences. And I will be next to you translating for the Argentine public, making sure everyone gets both the joke, the life lesson and the sociological implication of your stories.

*—Rodolfo Elbert, January 5, 2019*

Dear Erik,

I have such a vivid memory of the day that I met you. You were in the audience, in 2004, at our ASA session on the gendered effects of family leave policies. I was “debating” Barbara Bergmann, with Nancy Folbre and Paula England moderating. You were in the room, madly taking notes. I knew your work but not your face. I



whispered to Nancy: “\*Who\* is that man, with the great hair, enthusiastically writing notes?” She said: “That’s Erik Wright!” I think I said: “...Wow! Erik Wright!”

After the session, you bounded up to me with your electric smile and said: “Do you know what the Real Utopias Project is? I want to do a volume on this topic!” As I’ve told countless colleagues and students, collaborating with you on our “Gender Equality” RUP volume was one of the highlights of my life. You designed and provided a setting, for all involved, that was nearly perfect for exchanging ideas and learning. And, we had fun. I will cherish that book forever, as it embodies you in so many ways.

However many days you have left – be that few or many – I wish you peace, and light, and comfort.

I send love to you and Marcia,  
Janet

—Janet Gornick, January 5, 2019

Profesor Wright,  
As an undergraduate student in Chile in the 1990s, I learned it was possible to study social classes from a Marxist perspective reading your books with passion. My best wishes to you.

—Ricardo Rivas, January 5, 2019

Oh, Professor, I’m so sorry to hear this news. I heard you speak in Taiwan at Academia Sinica about five years ago on real utopias and found myself in tears at the hope the talk inspired. You just hugged me. You are a one of a kind human being that I’ve never forgotten. Thank you for all you have done. Wring as much joy out of your remaining time as you can. Love always.

—Neesha Wolf, January 5, 2019

Dear Erik:

I am very sorry to hear this news. Your work was an inspiration for me—a Chilean sociologist interested in class structure and consciousness in Latin America. Your book “Classes” taught me that that it is possible to be a Marxist and be honestly interested in rigorous, “conventional” empirical research. This, of course, was illuminating to me as it contradicted what many sociologists used to think. We met and chat a couple of times—one at ASA and other academic instances, and the last one in Buenos Aires in 2015, when Rodolfo Elbert invited me to attend your workshops and lectures at Universidad de Buenos Aires. This last time I traveled from Chile, and even the informal talks with you were an incredibly exiting intellectual experience. Thank you for all you have done. My thoughts are with you and your family. All the best.

—Pablo Perez, January 5, 2019

Dear Erik:

I am saddened to learn that your health has taken such a turn, and I wish to share this with you. My experience as a student in your graduate seminars was formative: you taught me what it means to be a caring and careful graduate instructor. There isn't a day I am teaching a seminar that I don't think about your skills in a classroom and your boundless energy that I try hard to (only, alas) approximate. Thank you for that. My favorite memory, however, is outside the classroom, playing banjo to your fiddle at Commie Camp. Thank you for these inspirations.

Jon

*—Jon Goldberg-Hiller, January 6, 2019*

Best wishes to you and your family, Erik. Know that you've influenced and enriched the lives of many others.

*—Michael Pierse, January 6, 2019*

Dear Prof Erik,

I am an admirer of your writing and thoughts. I am from Indonesia & a PhD candidate at Seoul National University in Social Dentistry major. As our knowledge, my article is the first study about neomarxian social class related oral health. It is an honour if it can contribute to your future writing even just for a bit. I hope Allah (God ) will give you more opportunity to contribute to the world. Aameen.

Best Regards,  
Herry Novrinda

*—Herry Novrinda, January 6, 2019*

Erik, we have never met but I have long admired your work. I am so terribly sorry to hear this. It is incredibly cruel, at such a comparatively young age. I hope your final weeks are as pain free as possible and that you can be surrounded by those you love. You will leave a lasting intellectual legacy, for which so many of us are grateful.

*—Lee Jones, January 6, 2019*

I am so sorry to hear this, Erik. You have been a huge inspiration to me and thousands and thousands of other scholars, your work is timeless. Your work on building real utopias has been used heavily in the latest Plaid Cymru manifesto, for example. Your scholarship has and will continue to drive tangible improvements in people's daily lives, thank you for everything comrade

*—Daniel Evans, January 6, 2019*

Dear Erik, I have always admired your energy and excitement about life and ideas. And I owe you so much for where I am today, especially my confidence. To a lowly undergraduate student from Croatia, you have been exceptionally kind and supportive. What I appreciate the most is that you have always treated me as an equal

and gave me the same kind of attention as you would give folks who are much higher on the prestige ladder. I will also cherish our Croatian and Bosnian adventures. I am sending you my best wishes and my thoughts. With love and gratitude, Valerio.

—Valerio Bacak, January 6, 2019

Dear Erik;

Your books are a very important source of inspiration to me. Besides, I visited you 15 years ago, and I could see your great humanity. I am glad to meet you in this life. Best regards

—Jose Saturnino Martínez García, January 6, 2019

Oh Erik, this is such awful news. You may not recall, but you and I had two long, and to me, very meaningful conversations over these last many years. The first was a job interview at a hotel during an ASA meeting when I was looking for a job, and the second was a couple of years ago after I had spent a week as a Visiting Fellow at the Havens Center, and we had dinner together on my last night in Madison. At the end of both conversations, and thus over the course of a 35 year period, I came away not just rejuvenated and challenged and stimulated by you at an intellectual level, but also deeply moved by what a truly good and decent person you were, and are. For all of the deserved acclaim and recognition you have received over the years, I hope it is known just how much of a mensch you are as a human being. With all my gratitude and good wishes and hope for you, Rick Fantasia.

—Rick Fantasia, January 6, 2019

Erik, I wish I could comfort you in some way, perhaps recalling the meetings in frozen Moscow, or in warm Grenada with the little adventures of the travel thru Sierra Nevada, or in harsh Madrid and the chistu with tamboril you got signed by the Spanish ECBC group, or in far, distant Canberra. Old, lovely years, for always associated with the clarity of your thought, the amenity of your story-telling and the warmth of your friendship. With love and gratitude, un fuerte abrazo. Julio,

—JULIO CARABANA MORALES, January 6, 2019

Dear Erik,

Thank you so much for all you've done. I took your class as a graduate student and it was my absolute favorite class. And, your work has been central to my thinking. I wish you and your family wonderful days in these last three or four weeks. Thank you so much for being such an inspiration to me and thousands of others.

—Quentin Wheeler-Bell, January 6, 2019

Dear Eric,

I remember, as a then graduate student, your visit to University of Hawaii in the mid 1990s and the dinner with faculty and graduate students after your talk to the Sociology Dept. on class analysis and the middle class. There

were heavy hitting faculty at that dinner, but you showed as much sincere interest in our research as in your esteemed faculty colleagues.

Your rigorous academic standards and enthusiastic dedication to students remind me of my late mentor Peter Manicas, with whom classmates and I discussed and debated your theoretical arguments throughout my time in Hawaii.

Grateful to have had the chance to learn from your example as a Marxist educator, activist, and a good human being, and, when possible 'pay it forward, ' as a professor in St. Cloud, MN.

Steve Philion

*—Stephen Philion, January 6, 2019*

Hi Eric,

I am writing from Turkey, where your three books on social classes are translated into Turkish in the last two years. I wanted to inform you that we, students of sociology who enjoy critical perspective, continue to understand the society with your contributions.

Best regards,

Metin Ozugurlu

(Faculty of Political Science, Ankara University)

*—Metin Ozugurlu, January 7, 2019*

Dear Eric,

I had heard of your illness from mutual friends, but having just now been forwarded - all the way from England - your latest posting on this site, I would like you to know that I will always especially remember the warm hospitality in your home and the stimulating discussions you hosted there as well as at the Havens Center both the times you invited me to speak at Madison. That this was my experience on visits there which spanned a quarter of a century - from the late 1980s to the one just a few years ago - only confirms how consistent and long-standing has been your role in sustaining the socialist intellectual community across the generations. For this you deserve a hearty bravo from all of us who have shared this commitment. My thoughts are with you.

With very warm regards,

Leo

*—Leo Panitch, January 7, 2019*

Hi Erik, I just read your letter and I am shocked by the sad news. I should tell you that I secretly believed that you were to be there forever and that I could turn to you like when, a few years ago, we renewed our contact suddenly over my desire and intention to be the translator of your new book. The feedback and strong support you gave me then only reminded me of the kind of person you are, and what you have meant to me in my elaboration of my political and academic interests. You are one of those rare teachers, and in my case the best by far, who really left an indelible memory in my person. I remember with Julio those crazy days in Granada and your furious driving down that hill without brakes. Was that Erik? Yes, he was Erik. Let's hope now that Erik surprises us again. I know you are fighting back. All my love to you, Marsha, Jenny, Rebeca and grandchildren of yours.

—*Natalia García-Pardo, January 7, 2019*

Dear Erik, I am writing from Ukraine where you brought an incredible amount of inspiration, energy and support to all of us who were lucky to meet you, and read your books and reviews on our work. I am grateful to you on giving me confidence in what I am doing. It was so shocking to heard about your illness, and all our thoughts are with you these days. You are and will always be a source of inspirational ideation to us.

With most warm regards,

Svitlana Khutka, Kyiv-Mohyla Academy, Ukraine

—*Svitlana Khutka, January 7, 2019*

Dear Erik

I have followed your blog for the last year with all the hope you will recover. Meeting you, reading your books, hearing your lectures, translating some articles of you was of tremendous importance to me. You have inspired my work on transformation. For all this many thanks. As our friend Marx said: the real wealth are human relations. So you are enriching all of us.

If it happens as your doctors are afraid I should say farewell until we meet on the other side,

in admiration for your work and for the man,

Micha

—*Michael Brie, January 7, 2019*

COME, said my soul,  
Such versed for my Body let us write (for we are one),  
That should I after death invisibly return,  
Or, long, long hence, in other spheres,  
There to some group of mates the chant resuming,  
(Tallying Earth's soil, trees, winds, tumultuous waves,)   
Ever with pleas'd smile I may keep on,  
Ever and ever yet the verses owning – as, first,  
I here and now, Signing for Soul and Body, set to them my  
name.

Walt Whitman

With love

Roberto fronte Italy

—*roberto mapelli, January 8, 2019*

Dear Erik,

Thanks for all your contributions to our understanding of Marxism, contradictory class positions and socialist politics. Sending you our warmest regards and an excerpt from a poem by Turkish communist poet Nazım Hikmet..

Sebnem Oguz, Ankara, Turkey

On Living

.. Let's say we're seriously ill, need surgery—  
which is to say we might not get up  
from the white table.

Even though it's impossible not to feel sad  
about going a little too soon,  
we'll still laugh at the jokes being told,  
we'll look out the window to see if it's raining,  
or still wait anxiously  
for the latest newscast. . .

Let's say we're at the front—

for something worth fighting for, say.

There, in the first offensive, on that very day,  
we might fall on our face, dead.

We'll know this with a curious anger,  
but we'll still worry ourselves to death  
about the outcome of the war, which could last years.

Let's say we're in prison

and close to fifty,

and we have eighteen more years, say,  
before the iron doors will open.

We'll still live with the outside,  
with its people and animals, struggle and wind—

I mean with the outside beyond the walls.

I mean, however and wherever we are,  
we must live as if we will never die.

Nazım Hikmet, 1948

—Sebnem Oguz, January 8, 2019

Dear Erik

Many thanks for your work on social class and for providing meaningful alternatives to capitalism. You might not remember but I also have to thank you for providing a detailed and constructed feedback to a conference paper of mine when I contacted you out of the blue. This shows the quality of you as a person and academic...

—Theo Krom, January 9, 2019

Compañero, agradezco inmensamente su gigantesca obra investigativa sobre las clases sociales en el capitalismo. Pocas veces existen intelectuales que combinen su nivel de inteligencia y de compromiso político con la construcción de una sociedad más justa que la contemporánea. Reciba también mi admiración por su encomiable acto generoso de hacer disponibles todos sus escritos en Internet de forma gratuita. Reciba un abrazo que perdurará hasta que hayamos eliminado todas las cadenas que nos oprimen...

—*Ramón Rosario, January 9, 2019*

Dear Brave Erik, here from Montevideo, remembering your succesful visit some years ago, embracing and supporting you in this journey. Best regards  
Marcelo

—*Marcelo Boado, January 10, 2019*

Erik,

I've only recently stumbled upon your work. It's amazing, not only intellectually, but in giving us hope for this world. May your time be well spent. You've certainly left a great contribution, and few scholars are getting the praise you are, for being a decent, caring, uplifting human being.

Best wishes,  
Thor

—*thor ribeiro, January 11, 2019*

Dearest Erik, Words cannot express my deepest appreciation of your generous intellectual and personal contribution to the development of Equality Studies and the School of Social Justice at UCD . In supporting us, and many other scholars and activists in Ireland, you have helped to keep the fire of resistance to injustice lighting, inside and outside the academy. Your spirit lives on Erik, inspiring and encouraging others to follow on your path. To me you epitomise 'The Good', that Brendan Kennelly wrote of in his poem, an extract from which I include here.

'The Good'

The good are vulnerable  
As any bird in flight,  
They do not think of safety,  
Are blind to possible extinction  
And when most vulnerable  
Are most themselves.  
The good are real as the sun,  
Are best perceived through clouds  
Of casual corruption



That cannot kill the luminous sufficiency  
That shines on city, sea and wilderness,  
Fastidiously revealing  
One man to another,  
Who yet will not accept  
Responsibilities of light.  
The good incline to praise,  
To have the knack of seeing that  
The best is not destroyed  
Although forever threatened.  
The good go naked in all weathers,  
And by their nakedness rebuke  
The small protective sanities  
That hide men from themselves.....

With Love and heartfelt thanks  
Kathleen

*—Kathleen Lynch, January 22, 2019*

## P.S. from Marcia

*January 4, 2019*

One caution: Erik is still quite vulnerable to infection, so, as much as he would like to see you, please do not come if you are at all ill. Even a cold.  
Thanks.

## Comments

Marcia, thank you! I just talked to Becky. I cannot leave until January 18, so we'll have to play it by ear. I'll keep healthy in the meanwhile. I love you.

*—Magali Larson, January 4, 2019*

Dear Erik, Marcia, and all - We have been planning to come to Madison for Myra's retirement conference and

we wanted to combine that with a visit . We so much want to see you all. We will keep in touch. Ron and I are both getting over a cold, but we will make sure to be OK by then. Love, MJ and Ron

—*Mary Jo Maynes, January 4, 2019*

Dear Marcia, I have been sending Erik my thoughts and love from a distance, but I want to make sure to send some to you too at this difficult difficult time.

—*Raka Ray, January 4, 2019*

Sending you lots of love, dear Marcia.

—*Szonja Ivester, January 4, 2019*

My heart goes out to you, dear Marcia, in this very difficult time. Sending you and Erik much love-

—*Masoud Movahed, January 4, 2019*

Dear Marcia, I think of you as much as of Erik during this terrible time, wishing you strength to bear it all. Love, Marianne

—*Marianne Ahrne, January 5, 2019*

Dear Marcia, You and Erik have always been an incredibly strong and warm-hearted team. Thanks for continuing to share so much of yourselves during this most challenging time. Wishing you continued resilience and joyful moments each day, Aimee

—*Aimee Dechter, January 5, 2019*

Dear Erik, I am glad you are not afraid. I met you in Stockholm, at the Institute for Futures Studies. Thanks for your wonderful books on class and socialism. They will be important and relevant for a long time.

—*Chandra Kumar, January 6, 2019*

## strange state of existence

*January 5, 2019*

I have roughly three weeks left of existence. Three weeks. Let's call that January, 2019. January 2019: my month, my last month. There can be surprises -- both ways of course. My liver is the main source of leukemia's havoc. It is greatly enlarged now, filled with AML. This is why I need transfusions of platelets and red blood cells every day. The graft did not survive the return of AML so it produces no products, and the AML-clogged liver seems to be filtering out some of the transfusions so I am not getting full benefit from those. The result is that my platelets remain extremely low even after a platelet transfusion and my hemoglobin remains very low even after a hemoglobin transfusion. So, eventually these become too low to sustain life, or an opportunistic infection does me in. The doctors say "a few weeks" -- a nice surprise would be to slide into February; my birthday is February 9. We'll see what happens.

This is all hard to take in fully. I am not in great turmoil over dying. I am sad about many things, desperately sad about those connected to my family. But I'm not afraid. I wrote about this early on; my feelings haven't changed: I am stardust that randomly ended up in this marvelous corner of the milky way where some stardust ended up in conditions where it became complexly organized in a way we term "alive." And then even more complexly—conscious stardust that is fully aware that it is conscious: amazing -- stardust, inanimate products of exploding supernova, organized in such a complex way that it is conscious of its own aliveness and consciousness -- the greatest privilege in the whole, immense universe. It may be for a limited time -- this complex organization ends and the stardust that is me will dissipate back to the more ordinary state of matter. Nothing to do about that. As creative fanciful minds, we humans are good at inventing ways for our existence as conscious beings to continue after the stardust dissipates. It would be nice. I don't believe in that sort of thing, but I'll find out by some time in February.

## Comments

We love you, Erik. Thank you for this, for your whole saga set down here, and, as you know, for much, more that this bit of stardust has contributed to the world. -- Jenny and Sandy

*—jane mansbridge, January 5, 2019*

earth to earth; ashes to ashes, stardust to stardust. If there were another side, I would look forward to seeing you there, in due course. But...I am another unbeliever...so I am with you in having no such expectation....but so very happy to have shared a bunch of time with you on the only side there is.

a big hug, Josh

*—Joshua Cohen, January 5, 2019*

It's impossible to read this without bursting into tears for anyone who knows you, dear Erik! You are one of a kind and we love you so much for what you have given us throughout your beautiful life and brilliant career. I will remain hopeful for great surprises to happen. Sending you and Marcia all the love I have!

*—Masoud Movahed, January 5, 2019*

Sending so much love, Eriki.

—*Gay Seidman, January 5, 2019*

Oh eriki. As always inspiring in me such awe, such incredible respect and boundless love. I picture your starburst playing a mean fiddle with an incredibly warm smile and great sense of playfulness and fun. I adore you. So glad for our lovely visit. Sending enormous love! So many years, so many memories!!! Thank you!!!! Xoxo, kathy

—*Kathy Cole-Kelly, January 5, 2019*

Stardust and so much more! Our meaning making is the deal. But some folks like you have the capacity to make meanings in so many ways. Analytically. Creatively. And of course, personally. And emotionally. There's the rub... Your many meanings will go on.

—*Mary Jo Maynes, January 5, 2019*

I teach a class in Alternative Social Possibilities up in Canada & your inspiring Envisioning Real Utopias is central to it. My students will be reading chapters from it in a couple weeks & we'll be thinking of you all the while dear Erik.

—*Mike Follert, January 5, 2019*

You are the brightest stardust that I have had the good fortune to meet. Keep on shining! Love you loads.

—*Szonja Ivester, January 5, 2019*

Dear Eric,

I was shocked to hear what you are going through. They are known cases where the patients could get rid of the illness. Why not you. Keep fighting. We all keep our finger crossed.

I remember your most successful visit to Prague in 2005. With warmest regards Tibor Vasko.

—*Tibor Vasko, January 6, 2019*

Erik, I happened to read Leibniz's Monadology last year. The reading somehow led me to think that we all come from the big bang that produced monads. For the first time in my life, I came to think half jokingly that I am indeed a cosmic being. Monad has energy and something like soul. I don't believe the soul part, but the fact that humans, like everything else, are cosmic beings made me happy somehow. Soul would not go on, but your legacy will go on. And I still hope you surprise all of us at the end of this month against all odds.

—*Keedon Kwon, January 6, 2019*

Dear Erik,

Very sad to read this. Happy to think about when we met in Stockholm, at IF and the lovely day at Artipelag with Stefan. We will for sure go ahead with the Real Utopia conference at IF.

With warmest regards,

Gustaf

*—Gustaf Arrhenius, January 6, 2019*

Dear Erik

Someday I hope to have your serenity in the face of my own limited time on earth. I've learned so much from you over the years, as a sociologist and scholar, but I wasn't expecting to continue learning from you in this way. But I have. Your hope, frankness, humor, and perseverance have been inspiring. I am still hoping it isn't so.

With love,

Tod

*—Tod Van Gunten, January 6, 2019*

I'm so sad to hear this latest news, Erik. Your insights and bravery during your difficult ordeal are an inspiration to us all. Let's hope we will both be around to celebrate our birthdays on February 9, 2019.

*—Arne Kalleberg, January 6, 2019*

Rik,

The many comments in the past day, and those of the past several months, reveal a minor flaw in your description of stardust to stardust. Some of your stardust has been embedded in the "conscious stardust" of others (friends, family, colleagues, students, students of students, etc.) who will carry it forward.

And some of your conscious stardust has been transformed into numerous books and articles, both digitally and in hard copy, to be read by untold numbers of people for years to come, who in turn will carry it forward. And closest of all your immediate family, in each of whom your stardust has been intricately infused in those most human of human, big and small ways -- and they will carry it forward.

We can discuss this proposed amendment when I see you in a few days.

Love,

Wally

*—Wally Rosenthal, January 6, 2019*

Thank you, Erik, for continuing to be a great thinker and teacher while enduring not only the terrible illness but also its terrible treatment. Through your chronicles of the past several months, we've learned a lot about both, and about the institutions and people on whom we all depend for good health. Your stamina, perseverance and outlook on the rest of your physical life are amazing. I continue to pray that you and your family have as many days and as much peace as possible.

Betty Thomson

*—Elizabeth Thomson, January 6, 2019*

Erik,

I have been thinking about you often since I heard you were ill. We only met a couple times, but participating in your workshop and enjoying a couple meals with you while I was doing fieldwork in Buenos Aires was such an inspiration for me as a sociologist. Your books sit on my desk, reminding me often of why I do what I do as a sociologist and as a person. I hope that you soak up the time with your beautiful family and friends.

Sending love,

Katie Sobering

*—Katie Sobering, January 6, 2019*

Our existence as conscious beings may come to a close for each of us, but our impact on the universe ripples out perpetually in ways small and large based on how we touched other people's lives. From a courtesy shown to a pedestrian to an epic love to a professional collaboration, we shape our world for good or ill. Yes, it's a structural conception of how we all "live on," but it's one that gives me comfort. And it's one that highlights all the good your life will keep sending out into the world for years to come, whatever may come for you as your Feb 9 birthday approaches. Mine's Feb 7, so I'll raise a glass for you as well on that day. --John

*—John Gastil, January 6, 2019*

I wish you and your family had not experienced this miserable disease. But your grace, courage (and curiosity) inspire. Your stardust has shone bright on so many--and this journal has illuminated living as well as dying. Wishing you as much time as possible with those you love.

I hope you enjoyed that sushi!!

Love,

Sonia

*—Sonia Baku, January 6, 2019*

Erik--I'm late to your Caring Bridge site but knew you were gravely ill. Thanks for sharing this--we all face death, just more or less immanent. I'm at the age where I like to hear how others are dealing with this reality at all stages.

I want to share an early memory of you--the first time we met I'm pretty sure. I'd come to give a talk at WI and was asked who I wanted to meet with. I mentioned you. I came with some question on my mind about class (can't remember details). I sheepishly threw it out in the first 3 minutes. BANG! We were off and running in an intellectual conversation. I sensed no big ego on either side. We just sought to explain ourselves and understand each other. It is conversations like that that are the richness of academic life--its lifeblood. Thanks.

I so admire your Real Utopias project. It will live on as an example for people on one way to combine intellectual integrity and progressive ideas.

Warmly, Paula

*—Paula England, January 6, 2019*

Erik,

It is incredibly inspiring to see that you are dying with the same courage, grace, intellect, and commitment to others that you have lived with.

*—William Roy, January 6, 2019*

Erik -- I've always thought of you as a bright and effervescent star. Your stardust has touched so many of us in so many wonderful ways. It will live on in all of us. With immense gratitude and love,

Anne

*—Anne Reynolds, January 6, 2019*

Joe had told us that you were unwell a little while ago, but, sadly, I only signed up to the journal very recently. As I read back through it, as I assuredly will, I know it will be a resource and 'a lesson in living', against the time that one will need it most. The timbre and tenor of your words remind me of a conversation (chez Joe, inevitably) many years ago when you gently made me recognise the glibness of my scepticism regarding the concept of utopia.

It's a crowded space, but my thoughts, love and respect, along with those of Filo, are with you, Marcia , Becky and Jenny.

*—Martin Kayman, January 6, 2019*

From the Joni Mitchell song...Woodstock.

We are stardust

We are golden

Keeping you and your family in the golden light. I appreciate immensely your willingness to share your life with us through this blog. Warmly, Ruth



—Ruth Powers, January 6, 2019

Beautiful

—Jennie Brand, January 6, 2019

Erik--

Your sharing is an enormous contribution to us all, and your power and strength a model. I simply want, first, to thank you for this and so much else that you have contributed; and second to tell you how important your life's work and your present example are and continue to be for all of us.

--

Onward on the course we all must follow, hopefully with the strength and lesson you offer!

Gar

—Gar Alperovitz, January 6, 2019

Dear Erik,

I have some words, but I am not sure they suffice to describe the impact the energy animating your words here has had on me the past few months.

Well, until I put my words together for you, I wanted to say this at least: I thought this in particular beautiful. "I am stardust that randomly ended up in this marvelous corner of the milky way where some stardust ended up in conditions where it became complexly organized in a way we term 'alive.'"

Living analytically and dying analytically... Poetic.

Perhaps I was thinking a bit on the meaning of life. What it means to be alive -- I mean beyond the physical sense of being alive -- when I started following your blog. You know, I have had a "platonic relationship with God", as one of Turkey's contemporary poets calls it, or, more accurately, with life beyond this one. A different dimension? Another product of our creative fanciful minds? Probably...But it is an appealing and sweet thought...

At any rate, I also wanted you to know that I am in Madison, and had every intention of seeing you, but it may be selfish to move to make that happen as I have a slight cold. This morning, Matias and I met with Jane Collins and Sandi Ramer and talked of you. (I do not know if I can post photos, but I will email you a photo today). We have so many good memories, and you are forever a part of a special community. We will all go, but our memories live on. Forever.

With love,

Ozlem

—Ozlem Altioğlu, January 6, 2019

Dear Erik,

I'm heartbroken at this news. As I said I would when I last wrote, I finished out my two-semester undergrad theory course with the third part of Envisioning Real Utopias. This reading is a revelation for my students, many of whom base their post-graduation plans on the typology of ruptural, interstitial, and symbiotic change you lay out there. In this sense, the stardust known as Erik Olin Wright has always been dissipating -- if we take dissipate to mean spread and expand rather than disappear.

Our son, Leo, was born on December 5th. We promise to pass on to him the lessons we have learned from you: how to stay committed to your morals and politics while acknowledging the limits of what you can know; the importance of making your ideas clear so that they are accessible to as many people as possible; and, most importantly, what it means to live as a true egalitarian.

With love and admiration,

chris, caitlin, and leo

*—Chris Muller, January 6, 2019*

The conscious part lives on too, in all our memories. Peace.

*—Kelly Raley, January 6, 2019*

Erik, I am so sad to hear your news. I have many fond memories of you--from the earliest, when I was in graduate school 40 years ago and you came to talk, to panels on Real Utopias at ASA. And of course our two weeks at the Havens Center in the 1990s. I will be thinking of you over these next weeks. With affection, Julie

*—Juliet Schor, January 6, 2019*

Dear Erik,

Grace and courage and optimism and kindness. All of these traits immediately come to mind when I think of you. Which is and has been often since we met in 1976 when I unceremoniously fell off a stack of computer output that I had piled high in my office across the hall from you, in hopes that I could reach something I'd stashed too high to retrieve. I landed with a thud and you came running in to make sure I was ok.

I have always admired and learned from your analytical brilliance, even when and perhaps especially when we disagreed. And if I have distanced myself intellectually somewhat over the years (though perhaps in some ways not all that far), it has been a protective move of a student asserting independence from an advisor. At this point however, I want to make clear and explicit in a way I perhaps never have in all these years that you always have been— and forever will be — an important intellectual influence on me.

Intellect as you know is important to me. But far more important are the qualities of caring and kindness and helpfulness and personal integrity and grace and in all these you provide a shining example. So it is no surprise how many other lives you have touched and made more meaningful in the process. Indeed, you are one of the

most fundamentally decent human beings I know. And this is a key part of your legacy.

I will be thinking of you and of Marcia and Jenny and Becky in the coming days. May they and you be enveloped in the warmth of love and family.

With great affection,  
Robin

*—Robin Stryker, January 6, 2019*

Erik, I am so sad to hear about this latest prognosis. The way you are dealing with it is inspirational. You have always been such a role model in everything you do and I am so lucky to have had the opportunity to work with you and be mentored by you. You and Marcia have been so generous to us over the years and you both taught us a lot about work, family and friendship. I wish I was closer and could come and visit and give you both a big hug. Unfortunately this is not possible. Please know that I am sending virtual hugs and lots of love to you, Marcia, Jenny and Becky every day.

Much love  
Janeen????

*—Janeen Baxter, January 6, 2019*

Oh my dearest Erik, no words can capture what you have given and what we lose. I am thankful for all of your words, those given to prove wisdom, kindness, comfort and hope. I just wish I could find the right words now. I love you and all you have given us, our world will not be the same without you.

*—SARAH S, January 6, 2019*

Hi Rik,

I, Carol and the rest of your Canadian extended family have been following your CaringBridge posts with admiration for your honesty and courage. The recent post that you titled "Grim Update" does, unfortunately, deserve that title. On the other hand, as you note, there can be surprises in both directions. We hope there will be a surprise in the good direction!

Whatever happens from here on, I hope that, as you think about your life, you feel as proud as I and many others do about your extraordinary accomplishments- both personal and professional.

You have lived the tradition of striving towards socialism that was established by our grandmother Sonia. You made really important contributions to the understanding of capitalism and the possibilities of realizing "real utopias". Your written works will continue to have positive effects on thousands of people. In addition, hundreds of colleagues and students have had the good fortune of learning directly from you, and many will pass your inspirational teachings on to their students.

I have been very privileged to share a grandmother with you. Our mutual love and respect for her is one of the many reasons that I feel close to you. I have greatly benefitted from your written works and from the many discussions that we had in person and by email. I have always really enjoyed the (not-frequent-enough) times that we spent together. I shall always remember dancing at my wedding while you fiddled!

Whenever I meet a sociologist, I brag that "Erik Olin Wright" is a cousin of mine. The response is always the same: "Really? He is a very distinguished sociologist." I respond "I know." But I also know what a wonderful human being you are.

Rik, I hope that things go as well as possible for you.

My love to you, and to Marcia and Jenny and Becky.

Peter

*—Peter Rosenthal, January 6, 2019*

Erik, you brought so much excitement and joy in our 3 years together at Lowell House '65-68, and your blog continues to inspire me and so many others.

hal

*—Hal Gabow, January 6, 2019*

Dear Erik,

Only now have I caught up with what is happening with you. I am so glad to be able to write to you in time to say how much I have valued our very longstanding, if intermittent, friendship. It began with my seeing you sitting on the ground in the quad in Balliol College, Oxford playing the flute. I was delighted when Christopher Hill sent you to study political theory with me, and I still recall what an exciting and exacting student you were. I remember a great visit with you to the Havens Center and a wonderful long country walk with you and your family. And subsequently always joyful encounters. And your pellucid, toughly argued, hope-sustaining writing. You are an inspiration.

*—Steven Lukes, January 6, 2019*

Dear Erik,

You have been a wonderful colleague. You were one of the first people I met when I came to Madison and we have aged together to become "old heads." Your dedication to and genuine interest in students has always been an inspiration. There will be a big Erik-sized hole but you have lived a life that has touched so many people in such positive ways that your spirit will always be with us. John and I are thinking of you and Marcia and Jenny and Rebecca and your grandchildren.

Pam

*—Pamela Oliver, January 6, 2019*

I love you, Erik, my own personal intergalactic storyteller.

JZ

*—Jonathan Zucker, January 6, 2019*

Dear Erik,

Andy and I are sending so much love and gratitude your way. You truly are a person who changed my life. It was your brainchild -- the Class Analysis Program -- that drew me to Madison so many years ago. You created a legitimate space in Sociology for leftist class analysis, and you encouraged rigorous radical thinking which informs me to this day. And on the personal front, I met my lifelong partner, Andy, and many close and treasured friends as a result of coming to Madison and being part of the program you created. Thank you. You made a difference in my life and the lives of so many others. We send our love to you and Marcia in this very difficult and precious time. --Wendy and Andy

*—Wendy Strimling, January 7, 2019*

Dear Erik

thank you again for the kindness you showed me as a young teacher on sabbatical visiting Madison in the 1990s. I have always treasured that walk we did around part of the lake when you didn't know me but invited me into your home. As to your work I have always liked its toughness. Exploitation is the basic dynamic of capital - you were always right. All the best for the coming days Georgina.

*—Georgina Murray, January 7, 2019*

Dear Erik,

Some stardusts leave a lasting mark on others. Your work is a source of inspiration for many, and Envisioning Real Utopias will certainly guide me for decades. It's a contribution to this incredible capacity of the stardusts that we are to critically reflect upon their condition and try to change it radically. May your real utopias be realized. Best wishes. Pierre-Etienne

*—Pierre-Etienne Vandamme, January 7, 2019*

Dear Erik,

On the stardust theme, I've been watching Cosmos (the excellent Neil deGrasse Tyson version) for the past few years with my son Miro. One of the segments that's made me happiest, or at least most at peace with life and death, is the Cosmic Calendar. If the Big Bang is on January 1st and the present moment is midnight on December 31st, the entire past four and a half centuries is merely one cosmic second. Everything that we obsess over in our lives is just a minuscule blip on the Cosmic Calendar.

Erik, you've made the most of that serendipitous moment when your particular spacedust took human form. Even on this blog, you've continued to spark new ways of seeing and living. I hope to never mourn the last days of a vacation again, and to savor them just as much as the rest of our time left.

You taught me a lot - to always engage with ideas in theory and in practice, to dream bigger, and to never stop learning and exploring. You inspired and deeply invested in my two biggest efforts to transform democracy, Making Democracy Fun & the Participatory Budgeting Project. Thank you.

When they're making the social science version of Cosmos many years from now, recounting our journey toward a deeper democracy and more utopian society, the segment on your life and work will sparkle.

Much love,  
Josh

—Josh Lerner, January 7, 2019

Erik,  
I'm so saddened to hear this news. But I wanted to thank you for the inspiration you have provided to me and so many others over the years. Only this past year, I and two of my colleagues started an undergraduate research project at UW-Eau Claire called "Real Eau-topias." Our university has declared "Equity, Diversity, and Inclusivity" to be some of its core values, and we are conducting focus groups with networks of students all over campus to find out, from a student perspective, how much our university is actually living up to those values and how it can do better. We are partnered with a student organization, Students Organizing for Community Action, and we hope to take the results of these focus groups and use them to push for some real change on campus.

It's a small thing, but the next generation of students is learning your vision for how sociology can contribute to building a just world. I teach your Contexts article on Real Utopias every time I teach Intro, and it will continue to be a cornerstone for me of social science that is empowering. Like stardust, your vision will live on.

All the best,  
Peter

—Peter Hart-Brinson, January 7, 2019

I wish our creativity was right, and you were destined to meet Professor Cohen and, as always, continue to illuminate our path with your work. However, my materialistic condition also prevents me. I'm sorry I never met you, and I hope, with all my heart, that the next few weeks are the best possible, writing and spending time with your loved ones and friends.

With warmth and deep admiration,

Thiago

—Thiago Celli, January 7, 2019

Dear Erik -- this is very sad news, even with a "stardust" outlook. I'm grateful every day for your contribution to my being able to have a career I love and value. I try to live up to the spirit of generosity you showed to me; no doubt I'm far from the only one -- so, part of a larger legacy, & a sense of a life very well lived.

David

—David Bartram, January 7, 2019

Dear Erik,

I am sad to learn of your illness, but have to say, I really love your stardust analogy. I certainly wasn't the best student, but you taught me a great deal. Jack Kloppenburg steered me to the 621 622 sequence my first semester in Madison and it changed me. For more than a few weeks it seemed I was learning a foreign language and progress was very slow! I think it is safe to say that your stardust rippled throughout the Madison campus strengthening pockets of critical thought and action in remote intellectual places like agriculture and food systems. Another bit of your stardust that will keep churning into the foreseeable future is the analytical tool of the 2x2 table. I teach this every single semester and use it to guide my students. I always think of you, and give you credit for teaching it to me, when I deploy it toward helping a student refine their research questions. Thank you for tolerating this slow learner but also for staying committed to emancipatory projects. -- Spence

—*Spencer Wood, January 7, 2019*

Dear Erik,

This is devastatingly sad. Your words continue to inspire, and it's been quite something to follow you on this difficult journey. As is true for many others, your work and guidance has meant a great deal to me. Your book with Archon turned me on to my life's work and your work as a whole has been very formative to my intellectual and political development. Your toughminded political optimism, logic and rigour continue to be a model to follow. I hope against hope you'll have some more time to inspire, and especially to spend time with your family.

Lots of love and energy,  
Gabe

—*Gabriel Hetland, January 7, 2019*

Hi, Erik. I just found out about your illness. Twenty-five years have passed since I spent a semester in Madison, enjoying your hospitality at the University, and it's been a long time since I had the chance to see you on one of your last visits to Spain, but the memories of the moments that I shared with you are alive and fresh. Your books had been a fundamental reference for my intellectual formation long before I knew you personally. The direct contact allowed me to appreciate that in your case the analytical rigor was linked to an incorruptible intellectual honesty, and, above all, it made me discover a warm person, always ready to give help, and with an exuberant vitality. All this makes me appreciate the enormous privilege of having crossed paths with you. I wish you the best for as long as possible. Miguel

—*Miguel Cainzos, January 7, 2019*

Dear Erik,

I just want to say how much our friendship has meant over these many years. To me, as to so many others, you're an incredible inspiration and example for how to lead a fantastic life as a scholar and person. Thank you



for teaching me the craft of social analysis and for showing me the power of curiosity and optimism.

Much Love,

archon

—Archon Fung, January 7, 2019

Dear Erik

My heart is with you. Your strength and courage are remarkable. I am so fortunate to have you as a cherished friend. I send you love and to Marsha and your family. You continue to be an inspiration as I read your words. You are more than stardust. You are a galaxy that will continue to bring light to this world. Thank you for you.

—Margie Mendell, January 7, 2019

Your unwavering commitment to an alternative world teaches us how to make the fullest of this amazing conscious existence. I aspire to live my temporary existence with a similar dedication for making this amazing existence amazingly astonishing.

—Amol Singh, January 7, 2019

Eric. You were my teacher in Fall 1987 at UC Berkeley, my first semester as a graduate student, and also then the single mother of a 3 year old. I recall your lucidity, the challenge to do all the readings, and the stretching of my mind as worked to write with clarity you demanded. In this moment I want to honor your long term commitment to a vision of more human world and thank you for all you taught me and so many others.

—Deborah Gerson, January 7, 2019

Dear Erik, you don't know me personally but have influenced me through your work for decades. I've known about your fight with AML for sometime, and your blog. I've not been able to read it though until very recently, as I lost my older sister to AML 20 years ago. You and your family have been in my thoughts for months. I so admire your courage and grace, and ability to share your experience of this life event that is so shrouded in our society. One more element of your important legacy. I'm hoping the doctors are wrong in their prediction of the time you have left - we found with my sister that its as much art as science, as so many of her doctor's predictions were wrong. In any case and outcome, count me as one more person thinking about you and your family and sending much love. Anne

—Anne Kane, January 8, 2019

Dearest Erik, you have been such an important person in my life: a friend, a mentor, a guiding intellectual presence, a north-point on the compass of my political imagination, and an inspiring model of a socially-engaged scholar and deeply kind human being.

You walk a few steps ahead on that path down which we all must follow shortly. In the time still allotted me I will endeavour as much as my abilities allow to continue the work and spirit of the Real Utopias project. It was your life's work, and is now mine. At the personal level you touched so many people's lives with your generosity and kindness. And at the macro-level you helped move forward the great struggle of our times – towards a reimagining of a just, democratic socialist alternative. We all see a little further and a little clearer now from our perch atop your shoulders. I can hardly bear to imagine a world without you in it. Yet some small comfort resides in the fact that I know that as long as I can read and write I will invariably hear your voice in my head, and as long as I see attempts to build alternative democratic structures in the world, I will feel your presence in them.

With love and solidarity, forever.

tom

—Tom Malleson, January 8, 2019

Dear Erik, I wanted you to know how much I value you personally, your Real Utopias contribution and your writing. I have valued our discussions over the years, your hospitality in Wisconsin and your vitality and wisdom. I still remember the conference in Wisconsin on UBI which influences me today. Recently I co-taught a course in Paris on the Future of the Left and used your material on what it means to be a socialist today. I am so deeply sorry to hear about your condition and send all best wishes to you and your extended family. Thinking of you so much at this time. With the fondest regards, deepest respect and profound admiration Ed

—Ed Miliband, January 8, 2019

Erik,

I am so upset to hear the news of your illness and prognosis. I remain grateful to you for the seriousness with which you read my work when I was a graduate student. And I recall with great pleasure the discussions we had on topics like “clender.” You and your work really helped me to find my place in the field when I was a young scholar, and I know that there are so many others for whom this is the case. Thank you!

—Elliot Weininger, January 8, 2019

Dear Erik, you will not remember me. I presented a paper together with a colleague of mine, Hayriye Erbas, on class structure in a Turkish town in the VIIth International Conference of the comparative Project on Class Structure and Class Consciousness, Granada, Spain, July 24-26, 1991. Your work on class helped sociologists all over the world to conceptualize inequality in their societies comparatively and to fight inequality using your vision of socialism. When a friend shared your 5th of January 2019 entry, I learned about "your strange state of existence" with deep sadness, and shared it with my mostly Turkish FB friends with following comments in Turkish: "Nur içinde, ???k içinde yatacak birisi çok emek verdi sosyoloji bilimine ve insanlar aras?nda e?itlik sa?lama mücadelesine". As someone contributing to the development of sociology and to the struggle for

equality be in eternal light in the state of complexity and in the dissipated state hereafter.

—Bahattin Aksit, January 9, 2019

Farewell Erik, hard as it is to embrace this word. Your influence on me has been indelible. I remember the very first moment we met in Madison. You asked me, "do you like the white stuff?", warning me of the snow that would soon fall and transform the world. And now you become stardust. You will fall like snow on my world. Thank you, thank you. Go well.

—Ivan Evans, January 9, 2019

Beautiful and brave words, Erik. Best wishes from Ireland.

—Michael Pierse, January 9, 2019

Dear professor Erik Olin Wright, I am sad that we will not be able to meet, but I want to say this: as a researcher in training, I have found your scholarly work profoundly influential. The Real Utopias project is the center of my interest, and as a researcher in training in the discipline of Futures Studies, I am trying to incorporate all your and your colleagues' insights into my work.

By all accounts, I have seen and heard that you are a bright, warm and caring person, someone concerned about making this world a fairer, sustainable, democratic, and overall better place.

I will tell you this: if it is within my life's possibilities, I will do my best to live by and develop knowledge using your contributions as a central reference. Your words in this post are both beautiful and saddening beyond words. José Saramago said: "The good and evil resulting from our words and deeds go on apportioning themselves, one assumes in a reasonably uniform and balanced way, throughout all the days to follow, including those endless days, when we shall not be here to find out, to congratulate ourselves or ask for pardon, indeed there are those who claim that this is the much talked of immortality." At least for the foreseeable future, your spirit, kindness and generosity will remain here, with us, trying to build a better future.

Your work and your life have made a mark in this universe, and though our existence is ephemeral, you can be sure that yours was meaningful. Go well, my heart is with you.

—Joshua Hurtado Hurtado, January 9, 2019

Hi Erik, and greetings from Ireland. I've been following your blog, and astounded by your courage. We appeared together in an edited collection last year from Lauren Langman and David Smith, and seeing my name on the same page as yours is a career highlight that will be hard to beat. I WhatsApp'd a photo of it straight to my wife and parents, and I don't think I did that when my first book arrived. I was hooked on Marx from day one - it was what converted me to sociology. I spent years working on ecology, and your work finally gave me the tools to explore class and inequality. It is a permanent feature of my work now, and there are many more who owe you a similar debt. We met many years ago in Ireland when you were president of the ASA - I was terrified but needn't have been. You were interested and questioning, and you gave me confidence during a difficult time when finishing my phd. I'm in the middle of a book you edited on social class from 2005 which featured John Goldthorpe and Richard Breen, and trying to explain the rise of the 1% in terms of rentierism and

a binary class model of earned vs unearned income. This is all influenced by your work on the systemic nature of social class. I just wanted to write and thank you for your work, for this blog, and to wish you all the best. I'm sorry we did not get to talk more. Eoin.

—Eoin Flaherty, January 9, 2019

Dear Erik, thank you for being you. You are widely loved and admired. Beyond consciousness and awareness and agency, one of the most redeeming features of our brief human state is our ability to experience and create meaning, including feelings and expressions of love, solidarity, compassion, in addition to flying kites, building stuff, exploring new things, or exploring social life and taking the time to consider why it has exhibited the properties and tendencies we observe and what to do about it. I remember your consistent kindness, helpful insights, and always compassionate spirit and they are a part of me and the lives of so many others. I remember your words of encouragement when I shared news of the birth of my first child ten years ago, several years after leaving Madison. And I have contemplated in last few days your reflections while observing and trying to make sense out of my own father's terminal illness. However fleeting, our lives continue to carry meaning for those who know and love us and it is this aspect of our lives that is celebrated and which survives us. Our relationship with you doesn't end. I only know you as one of too many graduate students who have passed through Madison WI during a fleeting moment of human history. But I know enough to thank you for being who you are and to pass on my strongest expressions of love, friendship, and thanks. Jonathan

—Jonathan London, January 9, 2019

Dear Erik

Thank you for your work and the generosity with which you shared it. I learned a lot from you not only from your books and articles but also from your posts in your blog. Your guide to reading Poulantzas and your syllabi have been particularly helpful for me. You threw light into many difficult problems. Reading you is always a pleasure and a first reference in whatever you wrote about, given the quality of your framing and treatment of problems. Thank you for showing how enriching a sociological perspective can be, by linking new development to the classics and working in theory all the way to empirical facts. With all the contingencies in this highly complex universe, it has been a great luck to have a great mind like yours paving the way for structural marxists. Greetings from Argentina.

—Maria A, January 14, 2019

## celebration time

January 7, 2019

Yesterday I made a wonderful discovery: I can dictate the stories and musings in the letter to grandchildren much faster than I can write them. I've developed a small tremor in my hands which increases the rate of typos. But even aside from that, Becky types vastly faster than I do. And my letter really is more like an oral story than it is like a written composition in many ways. So yesterday, I dictated the account of my falling in love and getting married to Marcia, and the beginning of the story of my going to Harvard and Oxford. Together those were about 6,000 words, which in one day was about 10% of what I had written since August. so I'll get a lot more storytelling done by dictating it. Also, it has the nice advantage that when there are visitors here it becomes a performance. And I'm telling stories to loved ones gathered around while Becky busily beavers away as my loyal secretary. I'm sure it will need some editing after it's done, but it's great fun to tell these stories out loud to Becky and for anyone who's around to hear them as well.

On a general health update, I'm actually feeling very good. Mind you, that's partially because of 4 mg of steroids plus 2 Ritalin. But they do seem to do the trick. It also seems that the new FDA chemo that I've been on for the last 6 weeks is slightly shrinking my liver, which is giving me some physical relief. Since this is a brand new medicine, who knows what it might do. It's nice to add a little uncertainty back into the story.

My daughters have given me a wonderful gift, and have organized their lives so that they can stay with me until I die. This really brings tremendous joy. I'm at peace with the situation and will just take things as they come. I asked the doctors what it is likely to be like at the very end, and they said I would just gradually be sleeping more and more of the day and eventually drift off into a sleep from which I don't wake up.

## Comments

How wonderful a discovery. And what a gift you are going to give to your family (and hopefully friends!). I am smiling and tearing up at the same time. Sending lots of love! BTW, can we send you real letters? Could someone post your mailing address?

—Rachel Schurman, January 7, 2019

Rachel - I hesitate to post it but you can call hospital - Froedert Hospital/Medical College of WI, Milwaukee. If the family has not asked for it not to be given to people, they will probably give it to you. Jody, Wisconsin

—Jody Whelden, January 7, 2019

This is great! Big, big hug!!!! - Jenny

—jane mansbridge, January 7, 2019

Storytelling... it is our way of telling the Little Ones who we are, what we have done, and where they have come from. Keep up those stories. You have an amazing capacity to weave stories. I know this from your classrooms (both real and virtual) and from personal experience. What an incredible thing to leave your grandchildren!

Hugs!

—*Szonja Ivester, January 7, 2019*

Dear Erik,

Your attitudes toward life and strategy of living are remarkable and inspirational--useful not only for the time that one is ill but for any stage in one's life as well. You are truly a grand murshid. I am also very happy to read that you feel better today.

Lots of love to you and Marcia

—*Mansoor moaddel, January 7, 2019*

I am so happy that you are feeling as you so well describe. I can imagine you telling out loud your love story with Marcia and I would like to be there to hear it. Damm! Erik, you are so special you deserve to last. And I bet you do.

Love and hugs to Marcia and those daughters whom I knew when they were born. A toast from Madrid!

—*Natalia García-Pardo, January 7, 2019*

Erik - Love this picture of family all around and Becky typing away. I remember when my mother was dying of stomach cancer a friend said to me , "She is giving you her final lessons." And so it goes with each generation, giving their final lessons to the next. Thanks for the great gift of sharing it with us. Love, Jody

—*Jody Whelden, January 7, 2019*

Dear Erik - Love, joy and peace - those are my very wishes for you!

It also occurred to me a couple days ago if you could dictate stories and letters to someone else (I was thinking about poor Marcia; had no idea your daughters were able to be around!), you could really accomplish a lot and it wouldn't hurt the quality of your stories or letters. The first time I was in your class, I took notes - as everyone else did, went home and read my notes, and boy, they were of publishable quality!

—*Cressida Lui, January 7, 2019*

I sent the following email to Erik a while ago, and wanted to share it.

Dear Erik,

Your recent messages "Time Horizon" and "nothing much to report" perfectly instantiate the extraordinary person you are and moved me to tears. They demonstrate in the most beautiful way your capacity to face reality in all its detail with almost casual detachment and your unwillingness ever to feel sorry for yourself. They also show your determination to move forward under difficult circumstances in the most sensible manner, taking advantage of every opportunity you have as optimistically as possible, but never entertaining illusions.

Over the many years I have known you, and not least on those occasions when we have had a chance to talk to one another about things we were going through at the moment, I have been simply blown away by your extraordinary courage, matter of factly expressed. Upon suffering a setback, even a big setback, you have always responded in the most productive way, with a discipline that has made my jaw drop.

You have always been an extraordinary inspiration to me, not to mention a generous and loving friend who takes the extra step to show support and deepen the relationship as much as possible. I am certain that very many of your friends feel the same way.

I want to send you all my love and let you know how much your continuing struggle means to me.

Bob

*—Robert Brenner, January 7, 2019*

I feel so happy for you, Marcia and your daughters. When my father was dying of cancer, we took the same decision. All the family gathered spontaneously around him in the house until he passed away. That was one of the best decision I ever took. These days together have bounded us and it helps a lot in the grieving process. Mindfulness dying is a rainbow of tears and joy.

*—Coline Ruwet, January 7, 2019*

Dear Erik

I am so sad to read about your illness but at the same time so incredibly moved by your wit and your astute evaluation of your condition, and by your meditations on life. I hope you know what an impact your work has made in South Africa, and on me in particular.

I am glad you are surrounded by love and friendship in the last weeks.

wishing peace and gentleness for you

Shireen

*—Shireen Hassim, January 7, 2019*

I have been reading all of your postings since the beginning and have been moved by them, often to tears. I haven't written anything in part because I've been so upset about what you're going through and also because it's often hard to know what to say, other than expressing how much we love and admire you. When I read today that Jenny and Becky we're with you I had to write since it brought back a flood of memories of joyous and fun filled moments raising our children together in what some of our students referred to as our little socialist republic. You've been such a wonderful father and friend and I have so much to thank you for and don't know where to start. Our many bicycle and ski vacations together were wonderful, including the one last year in Varoqua just before you fell ill. I hope we can all face death with the courage and optimism you've shown. As always we have so much to learn from you. MJ and I are planning to visit soon. A big hug to the only guy who has kissed me on the lips (during our ASA conference planning meeting in Denver when you were ASA President and wanted to make a point to the committee).



—Ron Aminzade, January 7, 2019

How wonderful to have Becky and Jenny there with you now, Erik. And that there is some physical relief... itself a relief to hear, and I do so hope that continues. And I trust that in your account of your and Marcia falling in love you've left room for your playing the flute on a bicycle while zooming through Cambridge? (I never could imagine how that was physically possible -- or perhaps I've revised the story in my mind via the scrim of literary dramatization...anyway always loved it. ) Love, Julia

—Julia Adams, January 7, 2019

Dear Erik,

It's wonderful that you are feeling well enough to share musings and stories that will be cherished by your grandchildren and generations to come. What a loving gift to them. I wish I could be there to see you and to hear about these important events in your life. Of course, even absent your account, imagining you and Marcia discovering one another makes me smile.

You are so kind to reassure your friends and admirers on Caring Bridge about the days that will come at the end. Always a dad, a beloved mentor, a devoted friend and caring colleague, you have looked after everyone and helped us prepare for our painful loss . You have taught us how to treat others in the best of times and the worst of times and through your generosity and kindness inspired others to be their best. Great thinkers, scholars, activists, and humanitarians leave legacies and often times acolytes. However, you will leave the planet with even more because you have shared so much of your inner self. Stem cells seem like an apt metaphor for what you have implanted in others. Your wisdom, knowledge, kindheartedness, humor and so much more will divide and grow in the many lives you have touched. You have an infinite store of love and affection that will live on in many hearts.

I hope you will continue to get relief and your body will cooperate for a much longer time than expected.

With great affection,  
Aimée

—Aimee Dechter, January 7, 2019

Hi Erik, I got a funny message from my brother Ashton today that I thought you'd appreciate. He had dinner last night with his friend Tony and Tony's mother, Magali , who live near him in Philadelphia. I stayed in Magali's house a few years ago while Ashton was sitting for her while she and Tony were in Italy, but never met her. Over dinner they made the connection to me living in Madison and knowing Gay and you. It's a small world, particularly the academic side, but its nice to have made the connection. I'm glad to see that you are in good spirits, despite the bad news, and that you are sharing memories with your grandchildren. Best wishes to you and to Marcia, Will

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—Will Jones, January 7, 2019

Dear Erik,

Thank you for everything you did for us as graduate students-- the careful selection of readings, the thought-provoking discussions, the painstaking work you put into reading everything I wrote, and the amazing feedback. I learned to be intellectually generous by watching you. In an earlier post (Jan 5) you talk about being stardust. Yes, you are because you've made such a difference in so many of our lives. Thank you. I look forward to reading your journal entries. Much love to you and yours.

—Sharmila Rudrappa, January 8, 2019

Dearest Erik,

Like so many others, I am heartbroken reading these latest posts. Also, like so many others, I am at a loss for words.

We met in the spring of 1995, when I enrolled in your 621 (Class, State, and Ideology) course. I still have my notes from the course, as well as a thick binder of readings. I was immensely happy while taking your course; in so many ways, it felt like coming home.

I will share one memory that I believe I shared with you when I graduated from UW, but I think bears sharing again now. Your class ran for a full two hours, and you allowed a brief break at the half-way point for students to go and get a coffee. One day, I was chatting with a fellow student on the break -- no doubt further exploring some point in your lecture -- and I missed my opportunity for coffee. Just as your lecture was about to start again, I complained (apparently loudly) about feeling tired. Strangely you disappeared, and I again regretted not taking advantage of the pause to go and get a coffee. Before I could finish this train of thought, you had reappeared with a mug of coffee, which you placed ceremoniously before me. "I wouldn't want you to feel tired," you explained with a wry smile, and began your lecture.

What I learned from you: learning works best when enveloped in love; love for students, love for the work, and love for the world.

I am forever grateful for all that you have given me, and I will never forget you.

With all my love,

Greta

—Greta Krippner, January 8, 2019

"It's nice to add a little uncertainty back into the story. " Ever funny, even now.

—John Gastil, January 8, 2019

First of all, all the best. Your thoughtfulness and good humor in facing the sad reality of mortality is really inspirational. Having said that, the body and modern medicine often surprise us, so who knows. As they say in sports, it's not over till it's over.

Just sharing one anecdote: I brought my dad to Madison for what turned out to be his last 18 months. After 15 months, he took a dramatic turn for the worse and it shortly became clear his body was failing. At virtually the same time, an owl took up residence in a tree behind my house and started waking me up at night with its hooting. I never heard any other owl in response so I was free to speculate as to the purpose of the vocalizations. The owl would hoot every night for a week or so, then disappear for 3 or 4 days before reappearing. I concluded that the owl was a messenger from my deceased mother telling the time was near and that my dad would soon leave me to rejoin her. I speculated that the disappearances were times when the owl was reporting back to my mom for updates. The second-to-last time the owl woke me up was the night before hospice called me to tell me the end was in sight. The last time was a week or so after he passed, which I took as an update to me that he was now happily back with my mom and all was well. I have not heard the owl since.

The great mystery of life is the spirit - that connection between our physical existence and our consciousness. Like you, I'm a non-believer in a traditional god. But it is also clear that there is so much we don't understand about life and spirit. If and when your mortal body gives out - which we all hope is far in the future - here's to that being the end of one journey and the start of another.

—Jody Knauss, January 8, 2019

Dear Eric: Thinking about you and Marcia and will continue to follow your posts , which have much meaning to me. Many caring thoughts from Ann Arbor to Milwaukee/Madison. Cousin Eve

—Eve Silberman, January 8, 2019

Dear Erik, I am so happy to see Marcia, Becky and Jenny and their families are there with you right now. I truly enjoyed being a part of all of your lives and I love you all. I can still picture our dinner and a pint while I was spending time in Ireland all those years ago. It was immensely gracious of you to take your time to see me while I was away from home and I will always picture us in Temple Bar together. Take care, your friend always,  
Brian

—Brian Pugh, January 8, 2019

Dear Erik & Marcia,

We have been so touched by your posts. Even though it has been years since we've seen you, we feel so very close to you both.

Erik, your posts remind me of an email you sent to your graduate students in Fall 1993. You wanted to allay our fears about your heart attack, confidently letting us know you would be fine and when you recovered, we would continue our plans to work together. We were moved to think that at that moment – just before entering the OR - you would consider our thoughts, our fears for our mentor. It speaks to your generosity of spirit.

Your posts here are similar: helping us to handle the news of your condition and with every keystroke, we hear

your voice indicating everything will be fine.

Our time in Madison was in many ways ideal: it is funny how I recall with such fondness the dinners with advisees, walking Ozzie afterward, the stories of your times in Berkeley, including seminary, or Oxford and your early days in Madison.

The way you accommodated a vegetarian with a wrinkle on a classic recipe, “The coqless coq au vin” which you uttered with a wry smile.

You helped make Madison a community of learning for all of us.

I find myself uttering brilliant phrases – telling a graduate student they are combining “a coarse-grained with a fine-grained analysis,” or at a practice job-talk, asking one of our graduate students: “so what’s the punchline?”.

The phrase I most associate with you, oddly enough, is not one of yours. It’s by E.B. White: “I arise in the morning torn between a desire to improve the world and a desire to enjoy the world. This makes it hard to plan the day.”

I frequently share this quote with my family and my students. Somehow, you seem to have found a way to do both consistently.

You and your family are in our thoughts. You have touched our lives. And made them better. Peace be with you.

Love,

Rob & Nancy

—*Rob Mackin, January 8, 2019*

Great!

—*Gustaf Arrhenius, January 8, 2019*

Dear Erik, Like so many other scholars around the world I have long admired your work, commitment, vision and optimism. Wishing you and your loved ones strength and peace.

—*Mervyn Horgan, January 8, 2019*

Dear Erik, my name is Tomás Rodríguez, I’m the editor of Akal, the Spanish publishing house of many of your amazing books. We spoke time ago about a translation.

I have read your posts with a mixture of complete grief and deep admiration. We are devastated with the news we read about your health, but also moved by your strength and integrity.

I just wanted to thank you for your teaching on behalf of your readers in the Spanish language. Thank you very much for your legacy, professor.

Un fuerte y caluroso abrazo,

—*Tomás Rodríguez, January 8, 2019*

Dear Professor,

I was a friend of your talented and beautiful daughter, Becky in high school. Years later as a doctoral student of Michael Apple's I read your book Envisioning Real Utopias right before completing and defending my dissertation. Your text enriched my perspective on my studies and the world. I reached out to you and you generously offered an opportunity to sit in on a few of your classes. You also met with me to discuss my study. I gained so much from those few hours of interaction that we had. You are truly a legend and I am grateful that I was present to some of your brilliance. I'm sending love and light to you and your family.

Thank you,  
-Beth

—Beth Sondel, January 8, 2019

Thanks for your lessons and commitment, reading you was key to my current understanding of things, and I really wish you can enjoy your family as much as possible. I send you a warm hug, as a comrade, as a student and as a human being. I send you a poem/song from here, from Chile, which I hope you like if you can read it.

Greetings,  
Diego

Volver a los 17 (Violeta Parra)

Returning to seventeen  
after having lived through a century  
is like deciphering signs  
without benefit of wisdom  
to be suddenly once again  
as fragile as one second  
to feel things as intensely  
as a child in front of God,  
that's what it is like for me  
in this very fertile instant

Chorus:

Gathering moss so the stone rolls  
like a thick ivy on the wall  
sprouting and sprouting so it grows  
like tender moss covering a stone  
like tender moss on a stone ay sí sí sí.

The steps I take all go backwards  
while theirs continue advancing  
the arch of our connections

has penetrated my nest  
in all its colorful swagger  
it's taken a walk down my veins  
and even the hardest of chains  
that destiny uses to bind us  
is like the finest of diamonds  
that lights up my calm soul

What feeling can bring about  
knowledge never could,  
nor the clearest course of action  
nor the grandest of all our thoughts.  
Everything is changed by a moment  
like an affable magician,  
it sweetly steers us away  
from bitterness and from violence  
only love with its science  
will turn us so innocent.

Love is a swirling whirlwind  
of primal purity  
even the wildest of beasts  
will whisper and trill its sweetness,  
it stops pilgrims in their travels,  
it liberates those imprisoned,  
love, with the tenderest of touches,  
turns the old (wo)man into a child  
and only the most loving care  
turns bad into pure and sincere.

Eventually the window  
was flung open as if by enchantment,  
and love entered with its blanket  
to give cover like a warm morning  
to the sound of its lovely reveille  
it made jasmine burst into bloom,  
and taking flight like an angel  
it hung earrings upon the heavens  
and my years of 17  
were transformed by the cherubim.

[Translation (c) Heidi Fischbach, 2014]

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—Diego Salazar, January 8, 2019

Dear Erik,

I found out a while back that you were sick, but honestly, I believed you'd have a good outcome and so I never looked for your writings here. But this weekend, news traveled of your recent health update and so I looked for your posts. I've read most of them, because of course, it's hard to put down something that is so well stated, so beautifully and honestly and lovingly crafted and of course, because I care about what is happening to you. I hesitated about posting a comment – you surely will be surprised to hear from me! – but then, just today, I learned of a little coincidence and so I decided to give it a go. And maybe it's important for you to know that there are people who, like me, think so highly of you, but who do not fit into the standard categories of family, colleague, student, lifelong friend. We crossed paths only occasionally, but over the span of many years and in the most curious circumstances: I was the spouse who came to dinner. I was the mom of YSP kids. We had friends and colleagues in common. And all that I can think of now is the brilliance of your smile, your thumbs up attitude toward my kids in their drama debuts, your delight in family, your love for great wit, for teaching, sharing, giving. It's impossible to cross paths with you and not to recall some big and small way where you said something extraordinarily generous and funny and good. As you say, we are the privileged stardust that briefly has experienced life. But once formed to think, act, feel, reason, there is something of us that stays. Call it love. I'm okay with that.

Here's the little coincidence that finally pushed me to write: Susannah's four year old, Serena, attends your granddaughter's school. The girls aren't in the same class, but Serena swears she knows Safira. (I do afternoon school pick up, so this is part of my world now too.) Connected now in this way, reaching out to you, Marcia, your daughters, to let you know that the list of people who care deeply is far longer than you could possibly imagine.

With love, always,

Nina

—Nina Camic, January 8, 2019

Mestre, são poucas vezes que podemos agradecer a gênios como o senhor. Obrigada por tudo e a luta continua o/

—Vanessa Ramos, January 8, 2019

Mestre, são poucas vezes que podemos agradecer a gênios como o senhor. Obrigada por tudo e a luta continua o/

—Vanessa Ramos, January 8, 2019

Dear Erik,

I sent you an email directly, but I wanted to add here how moving and inspiring your blog has been, amid the sadness.

I'm glad to hear there's new uncertainty!

Sending you love and strength from afar. Leslie



—Leslie Salzinger, January 8, 2019

Dear Erik, I'm deeply saddened to just recently learn about your health. You are among my most important mentors. From seminars at Berkeley about real utopias, to our time in Spain and Mondragon, and most recently when you spoke to my class via Skype, you have always been incredibly generous with your mind and heart. Your work and your being have inspired me in countless ways for which I'll always be grateful. I'm thinking of you and sending my love, Ofer

—Ofer sharone, January 9, 2019

It's so wonderful to hear that you can be with your family until the end, Erik! Reading your journal, I'm oft reminded of the way that capitalism strips these fundamental blessings from the ill and their families.

—Adam Szetela, January 9, 2019

Erik has been for us a real utopia as a sociologist and as a friend, for his intellectual contributions and for his values and feelings. What Michael Burawoy told us about Erik was real. When we met in Barcelona, the four of us were a team work plenty of collaboration and friendship, Erik called us: the Troika. In the Basque country, we worked very hard and enthusiastically with colleagues from the Mondragon Group, but we also have the opportunity to share our stories walking around Bilbao. In Göteborg, we shared a very special friendship in a dinner celebrating with Michael his election as President of ISA, when Erik was about to be president of ASA. In Wisconsin, Erik and his family were wonderful hosting Marta in their home. We like Erik, the friendship we share with other persons, the love for his beloved family. Sociology is lacking intellectuals and persons like Erik among its main representatives. With these real utopian persons is possible to believe and to work for the social real utopies, for a better world.

Your Troika (Ramon, Marta and Tere)

—Teresa Sordé, January 10, 2019

Estimado Erik. Muchas gracias por tu enorme contribución intelectual y política. Gracias por tu solidaridad al compartir tu legado con el mundo.

—Vinicio Coreas, January 10, 2019

We never met, but through your writings I found one of the best teachers I ever had. Your contribution to theory of social classes is well known, as well as your combination of political engagement with theoretical rigour. But now I also want to tell you that your honesty and enthusiasm had such a big impact on me, and that will remain. I feel very fortunate to count you among my teachers.

Thank you,

Pablo

*—Pablo Lapuente Tiana, January 10, 2019*

Dear Erik,

Your enormous intellectual effort seems to correspond to your love for your family and friends, admirable. The remaining task of others, who like me, are grateful to your writings and lessons? To keep your rigorous critical & radical spirit alive.

We will endure.

Love from the Basque Country,

Jon

*—Jon Las Heras, January 10, 2019*

Erik, I've just written you a private email. You will leave a great hole in my heart and my life with your departure. You, your contributions, your family represent all that is good and even great about humanity. Your intellectual life will live on and on and on and on. Of that I am certain.

With angst and love, Margaret

*—Margaret Levi, January 10, 2019*

Hi Erik,

I too have sent you a private email.

Love, Hillel

*—Hillel Steiner, January 10, 2019*

Dear Eric -- It is hard to find words at this moment. Nonetheless, I have to say that in the fifty-plus years I have been a social scientist, I have never known anyone in the profession as thoughtful, honest, and insightful as you, nor anyone who was as widely loved and consistently kind. Your example will be with us all for a long time. Thank you for all you have done and helped others do. Love, Sandy

*—Christopher Jencks, January 10, 2019*

Dear Eric,

One of the big joys of joining the P&S boards has been getting to know you. Your curiosity, vulnerability, intellect, and commitment to leaving behind a better world continue to inspire me and will remain with me and so many others. You are very much in my thoughts as you embark on this final stage of your journey, sending

you and your family love and peace from Vancouver.

Love,  
Antje

*—Antje Ellermann, January 10, 2019*

Erik,  
I hope I'm as strong and positive as you when my time comes. You've always been an inspiration to me, as a scholar, as a political thinker, and as a generous, caring, thoughtful person. You helped set me on my course as a sociologist and I'll always be grateful for your guidance, usually from afar, but still very meaningful. I'm sorry I put off joining the Politics and Society board for as long as I did. I would have enjoyed deliberating submissions with you. You've done a great deal of good in the world. And you've lived a joyful life. That's all any of us can do in our short time here.

Love,  
Joel

*—Joel Andreas, January 10, 2019*

Dear Erik,  
I heard today about your tragic illness. I will cherish the memories of the occasions we spent together, particularly when we were graduate students in Berkeley. I've written you at your ssc.wisc.edu address with some reminiscences, including the Berkeley graduate course you organized ("Commie course"), and the conference in the Sierra foothills (Commie Camp). Particularly memorable, now poignantly so, was your sendoff from Berkeley to Wisconsin: a river float trip for 75 friends and colleagues. I hope these memories will be as comforting to you, as they have been inspiring for me.

Your thoughtful, helpful, and considerate way of being in the world set the standards by which I would judge the essential worthiness of projects that we need to build democratic cultures and advance our understanding of global economic life.

With love to you, Marcia, and the family.

*—Clarence Lo, January 11, 2019*

Dear Erik and Marcia,  
I am so sad to hear of your illness Erik. You were both such good friends to my beloved Jerry and to me. I remember you in our garden after a meeting of the "non-bullshit" September group, and our lovely cycling through the Oxfordshire countryside. I still have your photos of those amazing yellow fields...  
Much love and solidarity,  
Michèle

*—Michèle Cohen, January 11, 2019*

Dear Erik

I heard about your illness in Brazil and I was cheering for a favorable outcome, like so many others who admire your work and you. Only yesterday I received information from this site and I became aware of the worsening of your health. I add my name to this chain of solidarity that extends to so many people and places. We will continue here inspiring in his work and spreading your ideas in Brazilian sociology.

I hope that this small manifestation (when adding to others) adds some comfort to you and your family in this difficult time.

José Alcides

*—José Alcides Figueiredo Santos, January 12, 2019*

## Christmas

*January 12, 2019*

I just discovered that I never posted this journal entry. I don't know how it works on the blog when one posts something from weeks past, but I will post it at than add a note in current time. [I now see that the posting just gets posted. So: what follows was actually written on Christmas day.]

It has been a while since I really felt able to write in a concentrated way, but real progress has been made on the various processes that were causing me to feel so badly the past week or so. **In any case, I feel** that I have crossed the "enough energy & focus to write" threshold.

Once again, the military metaphor: there is the war against AML swirling around me, but also battles with other foes, some closely connected to the AML, other's not. We cannot effectively take on the main enemy without defeating the other forces. A war on too many fronts. Well for the moment we're making progress on the immediate threats.

The big advance was on the bowel movement front. The standard treatment is an enema: A big bag of fluid is hung from an IV pole -- I don't know how much, but perhaps a liter. A long tube is inserted (gently, gently, ever so gently) through the rectum and then as far up into the colon as possible. The liquid drips into colon and after a while, 20-30 minutes, this triggers the needed action. That is standard enema procedure. Works well against standard constipation. My situation is a more complex because the constipation it partially the result of obstruction from the spleen and liver enlargement (I just found out that that liver was considerably enlarged as well). So, the more refined strategy: I lie on a table equipped with a CT-Scan which helps guide the enema tube as deep as possible into the colon to get to the blockage. Not at all painful, or even really uncomfortable. The table itself, mind you, was very uncomfortable -- hard, wooden table with no padding. It was also very high off

the ground -- maybe 4 feet -- and couldn't be lowered. The gurney couldn't be raised that high so I couldn't just scooch over from one surface to another. I got off the gurney, walked a few steps to The Table, and then with the assistance of a step, and hoisted myself up. It was hard. For anyone much more feeble than I, it would have been impossible. Once on the table, it was also supremely uncomfortable. I was asked to lie on my side, and the hard surface created a pressure point on my hip. The staff were nice, but then scene also felt a bit like gnomes doing their bit in a dudgeon. One of them had a very aromatic curry for lunch. Anyway, the The procedure itself went smoothly, without a hitch, then back to the room to wait for a dump, which happened a couple of hours later.

That was yesterday. Today I think my overall wellness has improved somewhat and things are on track.

Last night on Christmas Eve I happened to tune into the NBC Christmas Even service. The sermon was extraordinary. The preacher was an African American women named Jacqui Lewis. Here is how the sermon was described in the NBC press release:

“At the center of the Christmas story is hope...hope which comes to us in the form of a vulnerable, poor baby. A child, not a king, changes the world. God appears to us as a marginalized, Afro-Semitic, Jewish child from Nazareth in Palestine. A child who grows up to teach us to welcome the stranger. How would our world be different if we loved our neighbors as ourselves?” asks the Rev. Dr. Jacqui Lewis, senior minister of Middle Collegiate Church.

This barely captures the power of the sermon. Lewis talked about how the Christmas story was hijacked by imperialism and commodification -- power and greed. How once it became a state religion it was used for domination and exploitation. But, she says, the heart of Christianity is really simple. Strip it down to its core it is "Love. Period. The rest is commentary". Love, period, the rest is commentary. That is really potent o me right now. I see love at really a deep thread in my life, unifying how I teach, how I am a parent, my scholarly work and commitments to Marxism and emancipatory social science. To see this powerfully stated in a broadcast Christmas service moved me greatly. Of course, I can't accept all the God-talk, where good is a consciousness directly eternal all power Being. But when God is more elusive --God *is* Love rather than the God *Of* Love -- it is easier to swallow. Still, for me God detracts from the central message: love. period.

## Comments

So glad you reposted this! Love. Period.

—Gay Seidman, January 12, 2019

Or maybe Love is God?

—Joey Sprague, January 12, 2019

Thank you, Erik, for sharing this. Yours was a more difficult Christmas than mine -- than most people's. The

constipation-treatment event on the hard table and then love.... You know, the reason so many people care so much about how you are doing is exactly that. We\* felt\* the love with which you did your work, and the love that animated your relationships with us.

When I was in Madison, I visited the Pres House, the Presbyterian Church close to campus, you know. I don't know whether you continued to rent that second floor meeting room/lounge, but in our time (Fall 2005 to be exact), you taught Soc 621 there. It was a lovely room, with natural sunlight, and you, with your curly Afro-like hair lecturing at the top of the U-shaped table. Answering all the questions with care...

Love. Always.

—Ozlem Altioek, January 12, 2019

And you are love.

—Jennifer Wilgoeki, January 12, 2019

Love indeed--a truly emancipatory feeling. I am so glad to read that you feel a bit better today. Love.

—Mansoor moaddel, January 12, 2019

Have you ever heard the hymn “God is love and where true love is, God himself is there”? Regrettable pronoun but this chorus runs through my mind on a loop across these discussions.

—Myra Ferree, January 12, 2019

This is a wonderful and very powerful story, dear Erik! Love is indeed the ultimate meaning of existence; a means of existing and of causing to exist. Your commitment to the universal love is what also made us all fall in love with you. Sending you and Marcia all the love I have!

—Masoud Movahed, January 12, 2019

Love, period. Yes,. Wishing you nothing but love, Erik.

—Ivan Evans, January 12, 2019

I celebrate what you say. God detracts but also, god is the eternal mind for this power benighted species of ours. I am moved by the gospels, I confess. I'll see you very soon, now. Please be well. We love you so.

—Magali Larson, January 12, 2019

what a meaningful thread for a life

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—Carles Muntaner, January 14, 2019

"Love, period"--what a mantra for the architecture of a life...You've lived it, dear friend, and everyone ever around you has felt the aura of your love...

—Margaret Somers, January 14, 2019

## Twists and turns -- in paise of uncertainty

January 12, 2019

I'm sorry it has been a few days since my last blog. Partially this was a few days of feeling crummy, and then tons of visitors. Know this: If there is some dramatic turn for the worse, we will let you know on the blog, so "no news is goodish news" -- things are at least more or less stable. And is if there is some wonderful news, I'll let you know that as well.

The doctors came in for their daily consultation yesterday with a much more positive report. No more talk of "a few weeks left." While there is no mention of a long term or "survival", they spoke of a possible discharge from the hospital next week. I have apparently responded well to the new chemo I am on -- my blood numbers are good and my enlarged liver has shrunk a little. The result: I feel good, genuinely good -- no pain at all, modest energy, at what I call at ease in my body. Some of this is the steroid, I am sure, and some the Ritalin I am taking. But from whatever the source, I will take the good physical sense of well-being.

I am having a ball writing my letter to my grandkids. The discovery that (a) I can dictate text pretty well, especially stories/memories, and (b) Becky types @90 words a minute, almost without error, has meant that much more gets written each day: I have written 27,000 words over the past five days, while between August and the end of November I wrote about 55,000. This has made possible a delightful entertainment when we have visitors. They sit around informally, I tell stories from the 1960s and 1970s, and Becky types like a maniac. The other day I recounted the story of falling in love with Marcia, surrounded by people -- friends, students, family -- who love me. I found it wonderfully moving and fanciful.

## Comments

Good to have this report, Erik. Discharge from the hospital sounds like a great thing.

—Joshua Cohen, January 12, 2019

This is fantastic.

—Sarah Siskind, January 12, 2019

Good to hear this report. Love to you and Marcia from me, my husband Joe, my Mom, Carla, Jon and Nora.

—Andrea Kish, January 12, 2019

I'm very glad to have this news, Erik. Keep up the good work. Norma and I are in San Diego now, and we're thinking about you. Love to you and Marsha. E

—elliott sober, January 12, 2019

Rik,  
This medical update makes me feel a little better than at our goodbye Thursday. In "paise" of uncertainty, indeed!  
Wally

—Wallly Rosenthal, January 12, 2019

That is great news Rik! I am very glad that there has been some improvement in both the way you feel and in the short-term prognosis. Love, Peter

—Peter Rosenthal, January 12, 2019

Thank you (again), Erik.  
Hillel

—Hillel Steiner, January 12, 2019

Wonderful to hear!

—Tod Van Gunten, January 12, 2019

So good to hear from you and glad for your better news. Love to you and Marcia.  
Bobbie

—Barbara Marwell, January 12, 2019

We're on way! Just past the Dells. Can't wait to see you all and to join the audience for your stories?

—Mary Jo Maynes, January 12, 2019



Sweet Erik, This post puts a smile on my face! Hugs and kisses to you.

—*Szonja (Szelényi) Ivester, January 12, 2019*

Dear Erik, Thinking of you and joining you in praise of uncertainty—pleased at your more positive report! As a former student, I wanted you to know that you are remembered every day as I find the words and summon your inspirational vision for students in my own classes. And I am sure that there are generations of your students who share my feelings. Love to you and your family.

Maureen

—*Maureen Dolan, January 12, 2019*

Oh I'd love to hear the falling in love story!!! I'm sure I heard it before. Maybe time for an eriki podcast!!!!  
??? So glad you're having better days!!! Best news imaginable!!!!!! Much love! Kathy

—*Kathy Cole-Kelly, January 12, 2019*

Good to read you in a good mood. I wish you the best, you deserve it.

—*Diego Salazar, January 12, 2019*

Hi Erik, I'm glad to hear that the doctors have given a more positive report in recent days and that you feel pretty good. It's wonderful that you're able to share life stories and leave them for your grandchildren. I wish I could have been present to hear the story about you and Marcia.

I may be far from Wisconsin at the moment, but I'm keeping you in my thoughts. I'm in Jerusalem for a meeting at the Israel Institute for Advanced Study, but since the meeting isn't till tomorrow, I walked to the Western Wall today to say a little prayer for your health. I also wrote it down on a slip of paper, which I slid into the cracks of the wall, as is the custom here. You know, a prayer can't get any more direct than that—it's like registered mail or something. :-). It's said that the Shekhinah (Divine Presence) has never left the Western Wall, so I am hopeful she heard me today.

????? ??? ?????

—*Chad Goldberg, January 13, 2019*

Dear Erik and Marcia . I have just sent an email to and some pictures from the Leiulfsrud family. Love, Håkon

—*Håkon Leiulfsrud, January 13, 2019*

Yay!!

—*Patrick Barrett, January 13, 2019*

Hi Erik --

Hoping you are able to be discharged to home for a bit. Enjoying the thought of Becky typing 90 words a minute and recall that I used to hear you typing just about that fast from across the hall. What struck me then was not that you could type so fast but that you could THINK at 90 words a minute and it came out in coherent form (though perhaps not without typos).

Am assuming you are also recording your voice as you tell your wonderful stories for the grand kids, They will love to read the stories but my guess is they will also love to listen to them. Voices and intonation and emotional resonance are so evocative...

Sending you and Marcia hugs.  
Robin

*—Robin Stryker, January 13, 2019*

Erik, a posting on the Marxist Sociology email list provided a link to this site. I am so sorry to hear of your condition, but buoyed by your strength and courage and good will, evident on every page of this blog. As a long-ago grad student from another program (Mass Comm, early 1980s), I can certainly attest to your generosity, not only agreeing to allow me into your grad seminars but also supervising a prelim area. Definitely above and beyond. And I saw over and over the care and attention you gave to your students, about their personal lives as much as their intellectual development. Yes, definitely love. My best wishes: devour the time. David

*—David Amor, January 13, 2019*

Erik, this is such good news that the news is not all bad anymore and even contains an element of hope. How wonderful for you it would be for you to be able to escape the hospital for a while, although speaking from experience after months and months and months of continuous hospitalization, going out into the world is overwhelming, like the light from the sun is almost blinding. You will continue to be surrounded by the warm cushion of all your loving family and friends, as I know they feel so honored to be around you and share this whole story with you. I love your recounting how you're dictating your life's memories to you grandkids and the sheer joy it's bringing you. I can't even imagine the joy it will bring them.

As I've said to you elsewhere, your greatest gift of generosity to all of us has been your willingness to share the detailed processes of your treatment and your body's reactions to all of it. You have brought death out of the closet and helped all of us--at least me--face it by borrowing on your strength and Zen analysis. May you continue to be pain free, love Peggy

*—Margaret Somers, January 14, 2019*

## Reflections on generosity and kindness

*January 13, 2019*

I have been deeply moved by the way so many people have used the words "generosity" and "kindness" to describe me and my impact. Generosity and kindness are obviously virtues; the world would be a better place with more of both of these. But sometimes when people write so graciously and lovingly about my personal generosity and kindness they make it seem that these are not just admirable traits, but that they somehow involve sacrifices on my part, that being kind and generous is somehow heroic. It may be a bit unusual to find in an academic of my stature with these traits, but there is nothing heroic about this, no sacrifices. I feel that I live a more joyful life because I live this way.

I put a lot of effort into end of semester retreats with grad students. Yes, this is effort to be sure, but it helps foster a sense of community in which the dead serious work of sociology exists alongside of love and fun, where the competitiveness of academic life is a bit dampened. That is a better life for me as well as everyone else.

I live in a big house with spare rooms. Often we have people staying in one of those rooms. This does "count" as generous since under the rules of private property I "own" this space which gives me the right (and the power because the right is so heavily enforced by the state) to exclude anyone from access. But having people use the space to facilitate their lives contributes to a reality of living in a caring community which is, for me anyway, just a happier, more meaningful and fulfilling way to live, not a sacrifice.

Of course there are times when kindness and generosity take *time*, and given time scarcity that can be experienced internally as pressure and sometimes burden. But this is kind of the pressures and tradeoffs with parenting. This doesn't make generosity and kindness to one's children an heroic act of self-sacrifice. It makes parenting an act of love, in a context where there are too many things to do.

I know philosophers talk about character and personal virtues, and about cultivating one's character, and of course sociologists talk about socialization and norms which bear heavily on these issues. So does my thinking about real utopias, since one of the tasks of transformation and social emancipation is making a world in which it is easier for people to be kind and generous.

## Comments

These thoughts reflect true kindness and generosity of spirit!

*—Jennie Brand, January 13, 2019*

I love these thoughts, Erik, and so enjoyed your Christmas reflections on the sermon you heard. As it happens I

was visiting relatives (my partner's family) in Lawrence, your old stomping ground, and attended a Christmas service where the sermon was by an African American Episcopal priest. He too "politicized" love a bit in his comments. He almost worked up to "black lives matter" but didn't say it; but it was sure implied. (The Romans thought only Romans really counted, but Jesus was Jew...and that implied that other ethnic groups, other races counted...)

I also think about sociology and social engineering as partly setting the conditions to make care and kindness more likely. I think I was drawn to sociology to understand reasons for my mother's suffering Thanks for sharing and being you.

—Paula England, January 13, 2019

Thank you for these thoughts, Erik! You point to ways we can all improve and live more meaningful lives as a result.

—Mike McCarthy, January 13, 2019

All these may be true. But I think what people are resting to us that not enough of us exercise kindness and generosity. You do. And you always have. So there us something special to celebrate in your approach to people and the world. Thank you for being you! Hugs.

—Szónja (Szelényi) Ivester, January 13, 2019

Erik, I am really glad that you feel better and that the prospects aren't so gloomy. You are doing well in your war metaphor. And you even mention the possibility of being discharged from hospital. Specially great must be for you to be able to tell those stories that Becky types with such velocity and other people listen to, around you. As for your words over generosity and kindness not involving sacrifices, nor heroism, well, that may be true; but it is interesting you relate it to parenting in that sense. In fact I know by heart that you were a real good father figure for me. You trusted in me and gave me the confidence I needed. And you weren't just a good father figure. You were also a very intelligent and dedicated professor. And, then, you could also be fun. I always tell people how incredibly quick you were turning back comments on student papers. Comments were also extensive and to the point. Your notes on how to write short and long papers in 621-622, (I took them in 1982-83) have travelled along with me since. And I still find them inspiring.

So, Erik, my love and gratitude to you and to Marcia, who also gave me support when I badly needed it one year in Madison. Heroic may not be. But it is great when it happens. Much love to you both.

Natalia

—Natalia García-Pardo, January 13, 2019

Great thought, professor, I wholeheartedly agree with you. What I love about Aristotle is exactly this perception of virtues as not being "sacrifices". Virtues do take time and effort to develop and we must sometimes engage with the world in a way to reinforce our virtuous dispositions, but once we have the habit of generosity, for example, then we'll find true pleasure in our virtue. However, if we're not wise or generous, how are we

supposed to know the way of developing generosity? Surely, we shouldn't rely on spontaneity, nor on mere intellectual persuasion (for this isn't motivating in the Humean sense). This is exactly where sociologists, psychologists and philosophers need to work together in order to envision an environment of human flourishing, with institutions and stimuli that are able to "nudge" us into our better selves. I love this perspective of Ethics and Institutional Design as Ecology.

—*Fausto Pinheiro Junior, January 13, 2019*

Hi Erik,

As you know, I'm living in Honolulu this year, visiting the UH and doing my research (and visiting my mother and all my relatives). A local Lyft driver told me that there is no Aloha here any longer; too much money, greed, and tightfistedness have taken over. But I disagree. Yes, there are problems, but I see aloha here and in everything you've written. Kindness, generosity, and love are aloha. I like to think that you were influenced by your time studying and working here in Hawaii, but I think Beatrice and your father may have been the original sources. Big hugs, much love, Joan and Kjell

—*Joan Fujimura, January 13, 2019*

Henry James' advice for living a full life:

"Three things in human life are important. The first is to be kind. The second is to be kind. And the third is to be kind".

—*Connie Flanagan, January 13, 2019*

Your Christmas message is right on Eric ! We love you !

—*Pauline Thome, January 13, 2019*

"What do we live for, if not to make life less difficult for each other?" --George Eliot

—*Michele Rossi, January 13, 2019*

Erik,

Indeed, there is so much beauty here amid the tragedy and pain of your illness. Your words, everyone else's words -- such eloquent tribute to what seems to me the most important theme of your posts and everyone's replies: the real utopia of love.

I just heard that you may be coming to campus on Wednesday. Very much hoping to see you then.

Peace, paz, shalom, and salam,

Mike

—Mike Bell, January 13, 2019

Dear Erik:

sooo sad to hear this!! You have had a life that has given so much to your colleagues, to several knowledge domains...what a loss to all of us!

Your calm and clarity of mind are admirable, and this is what I will remember.

saskia sassen

—Saskia Sassen, January 14, 2019

Thank you for sharing your perspective and experiences with all of us, and for all that you've done for sociology.

—Amanda Maull, January 14, 2019

It's been 40 years, almost to the day, since I met you Erik. In the time since, I've never stopped admiring that character (and the more so, the more I got to know you): kind and generous, yes, but also brilliant, honest, earnest, humane, indefatigable on behalf of noble causes, small and large. It's been inspiring all through. Deep gratitude. Chas

—Charles Camic, January 14, 2019

I agree with your point about the virtues of generosity and kindness not requiring sacrifice or heroism but I think that the main point to make about your generosity and kindness is not only that it's almost an instinctual part of your continuous effort to build a loving and caring community but also that your expression of these virtues is oblivious to the entrenched status hierarchies of academia. It's expressed alongside your staunch commitment to equality so that it doesn't matter if you are interacting with an undergraduate trying to make sense of difficult material, a struggling young graduate student filled with self-doubts, an assistant professor worried about getting tenure, or a prominent world-renown scholar like yourself. You treat all of them as equally deserving of your kindness and generosity. I've always loved and admired your disdain of conventional and often taken-for-granted status hierarchies and your unwillingness to let them set boundaries on your effortless expression of kindness and generosity. Saying goodbye to you yesterday in Milwaukee was so difficult and tears are again flowing as I write this message so I need to stop here.

—Ron Aminzade, January 14, 2019

Erik, as you write about generosity and I read Ron's wonderful comments about your disdain for standard academic hierarchies of privilege and power, I'm reminded of the first time I had a real conversation with you. It was in Cambridge, at Gosta's apartment (probably when I was TA'ing for him in political sociology) and while I'd been around you and admired you for years, as a grad student I don't think I'd ever talked to you and I was of course totally intimidated. Somehow suddenly I found myself face to face with you and you were talking to me as though you'd known me for years and it was all par the course that a renowned star sociologist like you

would be having a perfectly normal conversation between equals with a nobody grad student. I was stunned...and felt like we were fast friends from then on.

Your gift is to make your generosity and kindness seem effortless and involving no sense of sacrifice; now I understand that that's always actually been true for you. In real life; in real time. What a gift to know you!

—Margaret Somers, January 14, 2019

Dear Erik, I was just reminded of the time we were headed to the ASA in Atlanta--the year you were the President or maybe President-Elect--and I made you wait with me for almost an hour at the baggage claim waiting for my suitcase--only to discover that my suitcase had been circling around the carousel the entire time, right in front of my eyes, but I didn't recognize it.

You were so gracious not to call me crazy. My excuse was that I was so engrossed in our conversation that I lost my mental facilities :)

I used that suitcase for years (it was "persimmon" colored) and always thought of you whenever I did. Such a funny embarrassing moment...

love, Peggy

—Margaret Somers, January 14, 2019

Erik, your last, revolutionary sentence both sums up what you are all about and the task that is left for all of us. Thank you. (And by the way....I've just finished my spring syllabus, which includes "American Society: How It Really Works." I always loved the statement in that book to effect of: "we've used the best data we can get our hands on. But if you have better data and can correct a point, let us know so we can improve." Such transparency and humility is another form of generosity for which we are grateful.)

—Thad Williamson, January 15, 2019

Dear Erik, I am a Chinese PhD student translated your article several months ago. So sad to hear this! And thank you for sharing your experience. We will continue building a better world!  
Shabai

—Shabai Mei, January 15, 2019

Hi Erik, you may or may not remember me, but I took a couple classes with you when doing my masters at Wisconsin in 2011-2012, and would just like to let you know the important impact you had on me. This was my first taste of graduate school, so I really had no idea what to expect as far as how helpful and receptive professors would be to my ideas, etc. I soon found out that most of those who I approached were not nearly as helpful or as receptive as you were. I can honestly say that I learned how to be a more honest and humble scholar as a result of your classes and the various conversations I had with you. It is extremely rare to find people who are so open about the weaknesses in their own arguments, and so willing to change their position when presented with evidence to the contrary. Learning this from you has allowed me to advance greatly in my own work, as I learned to question old dogmas and throw out dubious frameworks that were impeding my full understanding of various phenomena. If only all scholars and activists could be so honest! Thanks a million for

being who you are, for dedicating your life to helping others better understand the world, for helping so many young academics become better scholars, and for writing this wonderful blog reflecting on your life! You have been a model for more people than you even know!

Chris

*—Chris Carlson, January 16, 2019*

I've been reading your journal entries and thinking about you, Marcia, Becky, Jenny and your wonderful grandkids. I had such a delightful time when you came to Athens to give a talk on Real Utopias at UGA a couple years back: I'd always known you as a bright, witty, giving, and most of all FUN dad of my theatrical friends, so it was genuinely intellectually delightful and enlightening to meet and converse as adults and scholars. And also, you are still fun. What a joy (and not a surprise) to discover your talents as a writer, despite the suffering you've had to endure. We can't change our characters very easily and what I am is an optimist, I think, like you, so I basically cannot believe it's over yet, and am going to think that you'll be with us for more than a couple weeks. Hugs from me and my mom--who was here in Georgia a couple of weeks ago and reading your blog with me.

*—Miriam Jacobson, January 17, 2019*

## Message from Marcia about visits

*January 14, 2019*

Tomorrow, Tuesday, Erik is being discharged from the hospital. We will be living in an apartment close to the hospital. Discharges and moves are unpredictable, so tomorrow will not be a good day for spontaneous visits.

Wednesday, Erik is planning to be in Madison all day, so no visits that day either.

Becky has volunteered to do some basic scheduling of visits because the apartment is small and it is best to keep gatherings from getting too large.

Therefore, if you would like to visit, please text (not call) or email Becky. Here's the contact info:

Email: rebsonwright@gmail.com Cell for text: 608-695-3640.

Erik says this is not meant to reduce visits, just to make sure people will fit in the apartment.

Thanks.

## Comments

Funny, nice, postscript.



—Sarah Siskind, January 15, 2019

Thanks for letting us know, dear Marcia. Transitions can be challenging, but it's wonderful that Erik's condition will let you be together in a non-medicalized environment. May you have many lovely moments there!

Love-Sonia

—Sonia Baku, January 15, 2019

Hi Marcia and Erik, I wish you a peaceful time out of the hospital

Love and hugs,

Natalia

—Natalia García-Pardo, January 15, 2019

Erik,

Ever since last April, you have been teaching a master class on how to respond to a life threatening health challenge. Your master class has been a great gift to your family, friends, colleagues and comrades. Few, if any, of us can hope to be able replicate the lessons that it has encompassed, but none of us will forget them. Your frank acceptance of the reality of being under dire physical attack – no sugar coating – has been combined from beginning to end with savoring every successful strategy of resistance, however temporary or limited. You have stayed in the fray with energy and devotion, whether the news was bad or good, overcoming discouragement and moments of desperation, delighting in every visit and every outpouring of support. Somehow, you have transformed your master class on how to confront a deadly disease into a master class on love, on the value of love, on the intense pleasure and satisfaction of the love you share with those surrounding you, on how this love has become the most important dimension of your experience. We will always be grateful.

With much love, Peter

—Peter Evans, January 16, 2019

I could not agree more. Erik has given us another Master Class - this time on the importance of both resistance and love.

—Szonja (Szelényi) Ivester, January 17, 2019

Hi Erik I just wanted you to know I'm thinking of you with love and admiration. I admired your work as soon as I knew it, nearly 20 years before we met, was so pleased to get to know you back in 1998 when I first came to Madison (and met Harry for the first time too, without you that may never have happened!), and have so much enjoyed seeing you on and off - alas too little on, too much off - since then. You were an intellectual inspiration all along, became a personal inspiration as soon as I got to know you, and now I'm even more admiring, of your courage and clarity and open heartedness, in this final phase of your wonderfully lived life.

—Adam Swift, January 17, 2019

## A Week

*January 17, 2019*

Follow-up to blog on generosity and kindness:

I have been having further thoughts on my blog about kindness and generosity. There has been such an outpouring of appreciation from my students about these as qualities of my mentoring. But I don't think most of my students fully realize how much I have gotten from them. I may be generous and kind; true. But I flourish in my own work and development because of their hard work and the seriousness with which they engage their role as students.

Monday: Gathering of students in my hospital room:

Monday of this week was an amazing and profound experience for me. I had given up trying to coordinate visits because it had become too complicated for me and just told people to come whenever, so that if people overlapped, it didn't matter. On Monday, it turned out that about 25 former students and a few present students showed up in the late morning and afternoon, including a former student from Taiwan from the 1980s who brought his two daughters to meet me and students from every other decade. I told stories, they asked questions. At the end of the afternoon, I was sitting in a wheelchair near the door to my hospital room, and one by one, the students would come and kneel down to my level to say good-bye. It was truly beautiful and deeply meaningful for me.

Tuesday: Thwarted Plans:

I think I may have had the shortest discharge from a hospital on record on Tuesday. The plan had been for me to be discharged Tuesday by early afternoon to move back to the apartment to spend a few hours with Josh Whitford, Gianpaolo Biaocchi, and David James. I was indeed discharged, and managed to successfully get back to the apartment without too much hassle. We had been able to transfer apartments from the second floor to the first floor. In the end, I don't think I would have been able to manage the 14 stairs to the second floor; or at least it would have been a very big challenge. Along with the discharge procedures, we met with a hospice organization that would begin hospice services at our apartment on Thursday. It was really very reassuring for me to become part of the hospice program, which would basically provide the kind of more intensive nursing care and other services that I was familiar with on CFAC.

Josh had brought a fantastic video which begins with me giving a lecture on the shmoo and turns into a hilarious reading of the shmoo story by former students. What a wonderful, wonderful tribute. Here is the link:

[https://drive.google.com/open?id=1Nm xmSSd\\_Kk WfMRMh9t3z\\_2k5eakfDuw2](https://drive.google.com/open?id=1Nm xmSSd_Kk WfMRMh9t3z_2k5eakfDuw2)

As the afternoon wore on, of course I got tired; and basically when they left, I crashed. So far, so good. In the course of Tuesday night, we knew something was not good. The plan had been for me to go to Madison on Wednesday, to say good-bye to the department and to do a bit of preliminary work in my office to get things organized to make it easier to eventually clean it out.

Wednesday:

We took my temperature Wednesday morning and I had a significant fever spike of 101.9. So we called the clinic and they told me to go to the day hospital at Froedtert.

Going from our apartment to the day hospital turned out to be a horrendous and difficult task. I literally was unable to help in any way getting from the house to the car. I was a sack of potatoes for Adriano, Marcia, and Becky. Getting from the car into Froedtert was extremely difficult and painful.

I am sure that there are better techniques for doing this, but we sure didn't know them. It was bitterly cold for me even in the parking structure at Froedtert Hospital. I had been out of the hospital less than 24 hours and then was readmitted. Unfortunately, I lost my room in CFAC and had to accept a room on a general cancer ward in the hospital.

My room is about a third of the size of a CFAC room, but the staff and nurses are good and kind and responsive. I think things will be okay, but I'm hoping to move back to CFAC in the next couple days. I'm on a waiting list to get a bed in CFAC and I suspect that will happen.

It turns out that I have two infections, one viral, one bacterial, and they have really knocked me out. And also made me acutely aware of my level of vulnerability. I realize that how much time I have left is quite uncertain. If I manage to get on top of these infections, I could go for many weeks I think. But of course an infection can get out of control, in spite of the best care that you can imagine, and then I could be gone one day to the next. And I think this sense of uncertainty feels different from what I felt before. It seems silly at this point to talk about goals and things I still want to accomplish, but in these last weeks I really want to finish the letter to my grandchildren. I think I can with my speed demon Becky as secretary and my new-discovered ability to dictate text rather than just write it. So I'm hoping to be able to tell the stories of raising Jenny and Becky and what it has meant to me as an experience and as a font of meaning in my life to become a parent.

I adore this blog, which has become a kind of centerpiece in my life, it really has. It's helped me understand much more deeply than I think I could possibly have done otherwise, what it means to me to be dying. And the fact that I can share this in a simple way with the people who I love and the circle of students and friends and colleagues and apparently people I don't even know--that I can share this in a way that's proved to be meaningful to them has been such a gift. I think caringbridge is just an extraordinary platform, enabling in this case a life-enhancing mode of communication, which, for me anyway, has made this experience different. In the absence of caringbridge, I probably would have written notes, kept some kind of journal of my experience because that's what I do, but it wouldn't have any of this richness to me and of course I'm gratified that it's important to many of you as well.

Thursday:

Today I feel a little bit better than yesterday. The extreme weakness persists, and physical therapy will work with me to try to stabilize that. But basically until the virus that I have is under control and the bacterial infection is eliminated, I will continue to have this general problem of extreme weakness. My expectation at

this point is that I won't get another attempt at a discharge to the apartment. That I'm simply too precarious at this point. and even when I've overcome these immediate infections, without a well-functioning or even modestly functioning immune system, it's better to just stay within the confines of the hospital. But who knows. There are always surprises.

## Comments

You are amazing! Hugs, Joan

*—Joan Fujimura, January 17, 2019*

The struggle goes on Erik. Always!

Wishing for surprises.

With love,

Ozlem

*—Ozlem Altio, January 17, 2019*

Sending strength and admiration. Leslie

*—Leslie Salzinger, January 17, 2019*

Keep fighting, Erik! I have just bought a bus ticket to Milwaukee and will be dropping in to see you tomorrow. Til then, a luta continua! Keeping you in my thoughts.

*—Griffin McCarthy-Bur, January 17, 2019*

Keep up the good fight and high spirit.

You are in my thoughts.

Love

*—Mansoor moaddel, January 17, 2019*

You are such an extraordinary force of nature, dear Erik... Thank you so much for sending us these news despite your lack of energy, and ever seeking to see the light - beautiful side of life, however the circumstances. Love and peace of mind, i.

*—Isabelle F., January 17, 2019*

I'd like to add my voice to the chorus of people who get a lot of meaning and sense of connection from this blog, while being far from the circles you mentioned. We met briefly a few weeks ago when you Skyped the Toronto reading group. I (and we) have been so impacted by your academic work, and now your story here too.

I want to echo a sentiment I've read other commenters write elsewhere - that your life's work, care and attention will form ripples through time, the consequences of which none of us alive now can begin to imagine, but that will push people to taking better care of each other. And that you have had this impact on people like us, who you may have never even met in person.

Best of luck finishing the letter, with the next few weeks, and with the surprises to come.

—Tim Richardson, January 17, 2019

Thanks are due to Josh Whitford for organizing us all to make the video. I think it did us all good to do something celebratory. I wish I could come visit but am far away in Scotland. Sending lots of love.

—Tod Van Gunten, January 18, 2019

Oh Erik, so much love to you and your family, and so grateful that you're surrounded by your family and that extraordinary team of care workers at Froedtert.

I'm deeply moved by your desire to convey how much your life has been enriched by your relationships with your students. And so moved by the community of people you have connected here on caring bridge all sharing our love of you and our gratitude for our time together. In your reflections on kindness and generosity you're expressing again how love is at the core of your commitments, and the deep and rewarding reciprocity that entails. In the Times yesterday Leonhardt wrote a column, "students learn from the teachers they love," about the connection between learning and the emotional quality of relationships with teachers: "what teachers really teach is themselves—their contagious passion for their subjects and students." How very true of you, and what is more, as many others have also said here, you taught and keep teaching your contagious passion for life and love.

I've been reflecting a lot on how your commitments to family shaped my own orientation to life and love. By holding meetings and dinners for visiting scholars etc. in your home, so many of us students saw you caring alongside your scholarly work: connecting in various ways with Marcia and your kids, cooking dinner while talking about a project, taking a phone call from Jenny or Becky at college, packing up to visit your mother, and, in recent years, stepping away from meetings, receptions, etc. to sing "Dadoo's song" to your most cherished grandchildren over the phone. I deeply thank your family for their incredible kindness and generosity in sharing some of your family life with all of us, including in these recent months and weeks. I'm only now realizing how much I soaked up those lessons and how much your example profoundly influenced me in my own commitment to parenting while "professoring" (with lots of support from many people just as you have had, including my wonderful husband and extended family and highly supportive department culture and colleagues at OSU). Your delight in my children (well, all children!) and their total delight in you will always be among the most cherished memories of my life. You are so very beloved on this earth Erik. With profound gratitude and admiration and all hope for the best possible surprises, Rachel

—Rachel Dwyer, January 18, 2019

Hi Erik, glad to hear from you again. Lots of adventures you run these past days. Specially those 25 old students visiting you on monday. Some from the 80's, as myself. I wish I could have been there also. Sorry to hear that you got an infection and I do hope that you get back soon your CFAC room. It must make a difference. I am sure you will get enough energy to finish your letter to your grandchildren. I agree that CaringBridge, something I ignored it existed untill now, is a wonderful communicating experience for all of us. But it is you and your personality that makes it possible and I am happy that you do. Keep at it, Erik.  
Much much love from this student of yours from Spain.  
Natalia

*—Natalia García-Pardo, January 18, 2019*

## P.S. to last blog

*January 17, 2019*

We inadvertently forgot to include the link to the video. We've now added it to the last blog. Enjoy!

## Comments

Dear Erik, You probably do not remember me but as a fellow colleague via ASA, I always followed your work and have taught it extensively in my graduate classes at Loyola University Chicago. I just wanted to thank you for your wonderful insightful analysis both of Marxism, class struggle and the many debates my fellow professors have had over the years both in the Marxist ASA section and elsewhere. Your ideas will carry on because they combined both an empirical truthfulness as well as an attachment to struggle and human liberation which I and others admire. Your understanding of the nuances of social class also gave me a positive reason when I was doing research on homelessness and social movements to think of the abject poor not as lumpen but as actors in their own right. So thank you! Sincerely, Talmadge Wright, Professor Emeritus, Dept. of Sociology, Loyola University Chicago.

*—Talmadge Wright, January 18, 2019*

## Clarifying my final weeks

January 18, 2019

Yesterday, I had a bone marrow biopsy to see if there were any prospects at all of a rejuvenation of my bone marrow. Alas, there is not. My bone marrow is virtually empty and what cells are there are to a significant extent blasts. Dr. Michaelis told me that even if we were to wipe out the remaining blasts, I would be far too weak to even attempt another transplant. A transplant is off the table, and a transplant was always the only prospect for a cure. The only thing that's keeping me alive right now are blood transfusions of red blood cells and platelets. All of my platelets and all of my red blood cells come from donors, from ordinary blood donations. Unfortunately, the way this disease works is that gradually my liver especially, to use Dr. Michaelis' expression, chews up these transfusions, and you get increasingly less benefit from any given unit of blood. And at some point, no benefit whatsoever. You get a unit of blood, but your hemoglobin will not rise. And when that happens, you basically cannot sustain life any longer. So the scenario is basically when you approach that period--it doesn't happen abruptly, it happens over the course of days and weeks--you sleep more and more, your body is getting less and less oxygen, 15 hours a day, 18, 20, 24; you're not in a coma, you can be roused, have sweet words of love, maybe even more extended human communication than that. But then eventually you just begin to sleep all the time and, I assume, fade away. That would be the AML equivalent to dying in your sleep. You just, at one point, sleep 24 hours a day and don't wake up. But there are other potential scenarios as well. I have two infections, both of which could kill me, and those could blossom out of control and kill me one day to the next, blindsided. The doctors are doing everything they can to manage the infections and I feel my fevers are under control and that basically that's not likely to be the way that I die. But who knows. Maybe I'll be surprised. Marcia will update everybody when the time comes.

So, dear friends, what we've known for a while is in fact the case. I have a very limited time left in this marvelous form of stardust which I've been talking about over the past few months. I don't feel any dread. I want to assure you that I don't feel fear about this. It seems very petty to complain about the eventual dissipation of my stardust back into the stardust of the cosmos after having lived 72 years in this extraordinary form of existence that very few molecules in the entire universe get to experience. Indeed, to even use the word experience with respect to my stardust is amazing. Atoms don't have experiences. They're just stuff. That's all I really am is stuff. But stuff so complexly organized across several thresholds of stuff-complexity, that it's able to reflect upon its stuff-ness and what an extraordinary thing it has been to be alive and aware that it's alive and aware that it's aware that it's alive. And from that complexity comes the love and beauty and meaning that constitutes the life I've lived. And to top it off, I'm in this massively privileged corner of this human stuff that's managed against all odds to not live a life of fear and suffering from the cruelties of our civilization, that has never felt the fear of hunger, the fear of bodily insecurity in my neighborhoods, that has had the resources to raise my wonderful family, my children, in an environment where I think they too have felt physical security and the basic things you need to flourish. So there you have it. I am among the most advantaged, privileged, call it what you will, stardust in this immensely enormous universe for 72 years. And so it will end. But I knew that, at least from age 6. This is a few years earlier than I'd hoped, but no complaints. No complaints. And I suppose, to carry on this reverie a little bit longer, I suppose to top it all off, sometime in my late teens to early twenties, I decided to take advantage of this extraordinary privilege that I had, not to live a life of self-indulgence but to create meaning for myself and others by trying to make the world a better place. The particular way in which I did this of course is historically bounded by the intellectual currents and turmoil of the late 60s and early 70s. I don't think that means it should be thought of as merely an effect of that historical



moment. I think my dogged attempt to revitalize the Marxist tradition and make it more deeply relevant to social justice and social transformation today is grounded in a scientifically valid understanding of how the world actually works. But without being embedded in a social milieu where those ideas were debated and linked in both sensible and misguided ways to social movements, I would never have been able to pursue this particular set of ideas. But I was enabled, and it's made for an incredibly meaningful and intellectually exciting personal life. So no complaints. I will die in a few weeks, fulfilled. Not happy that I'm dying, but deeply happy with the life I've lived, and the life I've been able to share with all of you.

One final thought on this meandering theme: in November of 2015, I was hit broadside by a car while biking. It would have taken very little change in what actually happened to turn this from a significant injury into a death, from one moment to the next I could be here and gone. People sometimes speculate on what's the best way to die: suddenly or in your sleep, bang you're dead; or drawn out over an extended period of time. For me the answer is unequivocal: the death I'm having is the death I would choose. but there's one other little nuance of this way of dying that I didn't really understand beforehand. Often when people talk in a medical context about dying, when the context is the kind of death I'm dying, drawn out, people talk about the trade off between quality of life and extension of life. Well, what I've come to realize is that when you're really sick, when the pain of your illness takes over your life, or even when, as was the case last night I had uncontrollable and really hurtful coughing that kept me up most of the night, when you're no longer in your body in a comfortable way, that's not just a question of quality of life, that is a question of life. Five weeks of living the way I felt last night when I was coughing uncontrollably is not just some trade off with two weeks of living without it. Five weeks of living like that is not living. So I've told the doctors that from here on out, my priority really is comfort. Not being drugged so that I'm loopy and just feeling physically comfortable, I want to be mentally comfortable too. I want to connect and be able to continue writing this blog til the end. But my priority is to be present. And then let the length be what it is. It will end soon, hopefully it will last as long as possible, but only in the context of being truly alive.

## Comments

Dear Erik,

I send my caring and affection and deep respect and high regard to you. This is such a message of dignity and courage, you have inspired me more again as you have many times from afar. Joseph Blasi

*—Joseph Blasi, January 18, 2019*

Thanks a lot Rik. In addition to your teaching us how Marxism can be applied to obtain concrete goals in this epoch, you are now teaching all of us who are fortunate enough to be reading your blog how to deal with our own deaths. I hope that you remain comfortable enough to continue to enjoy your contact with family and friends for as long as possible. I hope you do not have prolonged periods of coughing such as you described, or other serious discomfort. A lot of people enjoy whatever contact we can have with you. If all we can have is your blog, we'll take it for as long as you can keep it up! Love, Peter



—Peter Rosenthal, January 18, 2019

Rik,  
Ever the philosopher-writer-teacher, with profoundly dialectical-materialist-personal lessons for us all. May the force be with your stardust today, tomorrow, and . . .  
With deep love and affection for you, Marcia, and your wonderful family,  
Your cousinly stardust,  
Wally

—Wally Rosenthal, January 18, 2019

Querido Erik, gracias por tus palabras, nos sigues enseñando hasta último momento. Te vamos a extrañar mucho y te queremos mucho.

—Rodolfo Elbert, January 18, 2019

Dear Erik,

Though you were my professor many years ago, and though Marcia is in the Feminar, it is with this blog that I've had the enormous good fortune of learning some of who you are. I knew the analytic sociologist, and the guy who talked movies in his office to a somewhat lost graduate student, but not the poet/philosopher who is reminding us of love, and sharing what it means to live as well as to die. I hope the drugs reduce your discomfort and the coughing disappears as you enter these final stages of living.

With love,  
Sonia

—Sonia Baku, January 18, 2019

Erik:

Thank you so much for the brave words and calm focus you send us all to the very end. I appreciate your inspiration and support today as much as I did 35 years ago.  
Love to you, Marcia, and the rest of your wonderful family,  
Vern Baxter

—vern baxter, January 18, 2019

thank you for sharing with us your life...and now your impending death. Jerry

—Jerry Himmelstein, January 18, 2019

Erik, I am learning so much from this and feeling so much what you say. Your blog has become very important

to me, and this note is the most important of all. Sandy and I have been reading you every day. He has been more hesitant to write, but I can tell you that what you write has had great meaning for both of us. Love, Jenny

—*jane mansbridge, January 18, 2019*

Hi, Erik--sorry I did not make it over today--I got a last minute call from Gay warning me that you might be overwhelmed with visitors today, and I think I missed the update that indicated that we should actually check in rather than drop in. I very much apologize for that. I wanted to let you know once more how meaningful it is to read these reflections and that David, Wendy, and I plan to visit you on Monday. We checked in with Becky this time so I think it should actually happen this time. Til then, sending you strength.

—*Griffin McCarthy-Bur, January 18, 2019*

Oh eriki, per usual this is brilliant, inspiring, sad cuz I love you and will miss you, and worthy of my rereading many many times. I love you, I cherish our more than 44 year history and relationship. I treasure the memories, the 'early days pre and with kids. From one stardust to another, sending so much love and comfort. Kathy

—*Kathy Cole-Kelly, January 18, 2019*

Thanks for including me in what I believe will be your final comments. I am so pleased to be a part of your family. JJ and Betsy

—*John Posner, January 18, 2019*

Dear Erik, You are amazing! Vish and I are totally inspired, moved, and dazed by you and your reflections. You continue to teach us so much about life, love, sharing, and being engaged in the world we live. Thank you for everything. With much love and admiration, Michelle and Vish

—*Michelle Williams, January 19, 2019*

My friend Erik - You've been continuously in my thoughts, and my heart, and will remain there till my dust follows yours back into the cosmos. Whether in a day, a year, or 50, this post will guide that journey just as your recorded stories once carried me off to sleep as a child. Clarity and radiance. Still boy wonder. So much love.

—*Brian Griffeth-Loeb, January 19, 2019*

Dear Erik, my heart goes out to you and your family. Again, we have never personally met, but your influence has certainly changed the course of my life and of the things I thought were both desirable and feasible. The words you have been writing have been truly inspiring, and it seems to me that I may learn as much from these blog posts as from your academic work. Love and best wishes, Joshua.

—*Joshua Hurtado Hurtado, January 19, 2019*

What a wonderful person you are, Eric. How happy surely are the members of your family and your close friends to have shared a part of their lives with you.

—*Haris Golemis, January 19, 2019*

I have been following you since before I registered here. Colleen your sister is our family here in Gainesville. I'm a still hopeful that I will meet you someday I'm a still hopeful that you will live. I don't know you and I love you. Thanks for sharing and thank you for existing.

—*Soraya Sus, January 19, 2019*

Thinking of you, Erik, and I'm grateful that I met and worked with you. Your essay and book on anti-capitalism will be a inspiring guide. Indeed, I had been around free marketeers so much that I had wondered if there were any people still left with thoughtful alternatives. I'm glad I found you and them.

—*Paul Dudenhefer, January 19, 2019*

Erik, I know this blog is largely about death, but I continue to learn and reflect so much on its meaning for life, and how to live it. I appreciate the perspective shift on how very privileged we are, and how to ground ourselves in that privilege of existence and experience as we interact with the history taking place around us, and by us. Thank you.

—*Josh Lerner, January 19, 2019*

Thinking of you, Erik, and wishing you ease as you make this journey. Much love, Becca

—*Becca Krantz, January 19, 2019*

My deepest, tearful gratitude to you, Erik, for everything you have done over many years and for so generously sharing your reflections, struggles and feelings with us in your entries. Thanks for your wonderfully loud celebration of life. May your time ahead continue to be filled with love, peace and comfort. Love you dearly.

—*Cressida Lui, January 19, 2019*

Dear Erik -- I wish we had had a chance to talk about all this before the end felt so imminent. But know that you have taught me more in the past month about how to think about death than I had imagined possible. For that I will, I hope, be grateful until the last. Sandy

—*Christopher Jencks, January 19, 2019*

Thinking of you, Erik. Hoping for comfort for you!

—*Mieke Meurs, January 19, 2019*

Erik,

Thank you for your posts. I will never forget you--so long as I remain alive. I should say "we," because I'm sure everyone else following you feels the same.

—David Schweickart, January 19, 2019

Dear Erik

Thank you for your posts. Thank you for being a model in life and work. Thinking of you, like yesterday and tomorrow.

—Carles Muntaner, January 19, 2019

Dearest Erik, You are my favorite stardust. I am not a religious person, but if ever my stardust with yours meets again, I'd like you to autograph another bottle of red wine for me. With gratitude and love, Szonja

—Szonja (Szelényi) Ivester, January 19, 2019

Hi Erik and Marcia

We're really sorry to hear there are no treatment options left. We are thinking of you both constantly and hoping that these final weeks stretch into months. You are both truly inspiring and wonderful role models and we love and admire you both enormously. We love this blog and it has been terrific to be able to follow this journey so closely with you even though we are so far away. We'll never forget working with you Erik and the wonderful life changing times we had in Madison on every visit.

Much much love

Janeen and Mark

xxxx

—Janeen Baxter, January 19, 2019

Hi Erik, I am deeply moved. I admire you most. You have been able to integrate your life and death in a beautifully designed analytical schema of yourself in the Universe. And you are so brave.! Thank- you Erik for this new astonishing display of yourself. I am sure I learn some about observing my own sunndurst transformation when it arrives. I am 71.

I consider my self so privileged for having being near you when I was young and eager and a left activist in Spain. And you were there for me at that moment to discover me the beauty of analytical rigor, and connecting theory and praxis. I was so happy then. You were a milestone in my life.

My father died in 1998. And I will feel an horfan when you die because you have been a second father to me. I shared with you and Marcia, besides, our parenting experience and I felt close to you.. The Waisman Center and all that. My son Lucas was in between Jenny and Rebeca, as you know, and I remember we shared talking about the quasi "religious" experience, you said, of coming out from the child bethroom, after putting them to sleep. Many things so important to me that I knew you valued equally and you shared. And you gave them a name.

I love you Erik and I want to be, and I am, by your side, with you, in this trance. I am and feel with you. I am profoundly sad. But. You are teaching us a great lesson in your last days by saying you have no complaints. We are so proud of you. You are a grand scientist and you have a huge heart. All my love Erik and family,  
Please don't suffer, but write back if you can

—*Natalia García-Pardo, January 19, 2019*

Erik, thank you for sharing yourself with the world. Even though we didn't work together, your real utopias project inspired me in graduate school. I sending you my best wishes. Peace, Gina

—*Gina Spitz, January 19, 2019*

Dear Erik,  
I was lucky to attend a session once in nyc in which you discussed organizing in these current super lean labor markets. Your great writings will live for many generations to come, and will open doors to countless inquirers. I wish you comfort and awareness till the very end.

—*Ahmad Al-Sholi, January 19, 2019*

Erik, I want you to know how much I value your willingness to share these moments with us. It has been quite a wild ride on this blog, but I am grateful that you have brought us along with you through all the twists and turns of the medical journey. I especially appreciate your willingness to be so open and forthright about your pending death and I hope I will, when my time comes, be equally able to be frank and fearless. You have lived your life's hours with gusto and joy and made this a better place for the rest of us. Thank you.

—*Myra Ferree, January 19, 2019*

I was lucky to have attended some of your lectures in NYU and the left forum. Your talk, books and illuminations inspired us all. I deeply appreciate you sharing these moments and reflections with us, it gives us a lot strength and confidence. You are in hearts and minds always.

—*Dego Adely, January 19, 2019*

My dear Eric,  
what ever happens, you will live in my heart. Tibor

—*Tibor Vasko, January 20, 2019*

Dear Erik,

I am reading this from Dar es Salaam, Tanzania. I am your distant student and comrade, I read your writings, especially Envisioning Real Utopias, and was so greatly influenced by them. We are actually putting them into

practice in Tanzania. I want to thank you for devoting your life to the cause of the working class.

In solidarity

Sabatho

—*Sabatho Nyamsenda, January 20, 2019*

Dear Erik,

I didn't know you before, but having read your blog, I find it very moving and feel that I know you now. When you return to stardust, you will have left something valuable behind for those of us who are still alive.

Best wishes for a peaceful and painless journey,

Rohini

—*Rohini Hensman, January 20, 2019*

Dear Eric,

We have been inspired by you so much as the generation of 78 in Turkey. Thank you so much for all your effort to do this planet best for all of us. I know hundreds of people will be with you with their love when you are leaving...

You will in our hearts until we leave.

Hatice Kurtulu? (Istanbul)

—*hatice kurtulus, January 20, 2019*

Hi Erik, we didn't know each other well when I was at UW, but I have always had so much respect for you and have been following your journal. Sending you and Marcia lots of love .

—*Karma Chávez, January 20, 2019*

Dear Erik,

You don't know me, but your work has been deeply influential to my growth as a sociologist a decade ago when I was in grad school. I remember the days when I poured over your work on class, and how much I enjoyed the process of getting to know your work.

I also had the privilege to have heard you speak at the ISA in 2014 at Yokohama. To be able to hear your firsthand, and hear about your experiences in Taiwan was really an amazing experience for me.

I am deeply saddened by your illness, but also amazed at the courage which you have faced it. Your words and reflections on existence and being stardust reminded me of another intellectual hero, Carl Sagan. Like you, he went off far too young, and people like you and him are desperately needed in times like these.

Sending you my best wishes, and hopes that when you rejoin the stars, it will be comfortable and painless.

Respectfully,  
Eugene

*—Eugene Liow, January 20, 2019*

Dear Erik:

It has been such an amazing privilege learning from you in so many ways. You have been a model for me as a scholar, as a colleague, as a community member, and as a human being. Just because most of us fail to emulate doesn't mean we haven't been deeply affected by having you pass by our sublunary sphere. You've pulled us all a bit in the direction of your wake. See you on the other side, Stardust.

Love,  
John

*—John Levi Martin, January 20, 2019*

Dear Erik,

I was saddened to hear about your illness. Thank you for sharing your experiences with others on your blog.

Your theory and analyses show the importance of Marx and class critique as long as capitalism is around. Your works have done and will continue in the years and decades to come to do a great job of introducing students and activists to the relevance of Marxist class theory and critical scholarship. Thank you for all the important work you have done.

Out of your work and life speaks a deep love of humans, the love of others, socialism as the society of love.

“If man is to be able to love, he must be put in his supreme place. The economic machine must serve him, rather than he serve it. He must be enabled to share experience, to share work, rather than, at best, share in profits. Society must be organized in such a way that man's social, loving nature is not separated from his social existence, but becomes one with it.

If it is true, as I have tried to show, that love is the only sane and satisfactory answer to the problem of human existence, then any society which excludes, relatively, the development of love, must in the long run perish of its own contradiction with the basic necessities of human nature. Talking of love is not ‘preaching’, for the simple reason that it means to speak of the fundamental and real need of every human being. This need has been obscured, which does not mean it does not exist. Analyzing the nature of love is to discover its general absence in the present and to criticize the social conditions responsible for this absence. Having faith in the possibility of love as a social phenomenon and not just an exceptional and individual one, is to have a rational faith based on understanding the nature of man.”

-- Erich Fromm: The Art of Loving

Best wishes, Christian

—*Christian Fuchs, January 20, 2019*

You are an inexhaustible source of inspiration, Erik. As a Marxist, as a sociologist and as a human being.

—*Ruy Braga, January 20, 2019*

My feelings exactly. Your work has been important to me. Thank you, thank you!

—*Barbara Ehrenreich, January 20, 2019*

Dear Erik,

here is one of the countless who read you avidly at some point of their student life. For me, this happened to be the case at a time of profound disappointment about socialist politics and pessimism concerning its rational foundations. You were among the half-dozen scholars who helped me out. Thanks in particular for the "What is AM?" paper. You guys were showing the red/expert space might be a tricky one, but there is no absolute tradeoff, and there are paths science and revolution can walk hand in hand. In doing this, you struck me for the absolute reluctance to buy into any sort of aesthetics of trenchancy and categorical posturing. Raising strong criticisms without making a carnage, and getting to work on them constructively as soon as they were clarified, is a rare virtue. The overall example you gave me is one of remarkable balance, good-naturedness and intellectual honesty. This image of you and the lesson it carries will endure, I suspect, for all my life. Goodbye

—*Matteo Pinna-Pintor, January 20, 2019*

A fellow sociologist who was a grad student at UW , from 64-68, before you arrived. Always enjoyed reading your work and now your moving thoughts on this site. We're all going to transform to stardust sooner or later and believing one has made the most of the opportunity we had in our human form makes for no regrets. I will send your last post to the blogosphere where it will also have a fruitful life.

—*Milt Mankoff, January 20, 2019*

Dear Erik, Your rigorous, elegant and thoughtful work on class is something I share with my students and use in my work: Recommended to me years ago by another dear Marxist friend. I am deeply saddened to hear how much you've been in pain; and hope for you the clarity and calm that you need for connecting and living as you wish to in the time that remains. I would be proud to feel as you do in the same situation. You continue to inspire. In friendship. Shakuntala. X

—*Shakuntala Banaji, January 20, 2019*

Dear Eric, I recall your generosity and kindness way back then when I spent a few days at your place in the heady days of 1993 when I was trying to make sense of the crazy events unfolding in South Africa. I remember how you laughed at the silly jacket and shoes I had brought with me from California and how you padded me



up to face the cold. As a subtropical gremlin, I really struggled to make sense of such sub-zero worlds, but what I did not struggle with was the clarity of discussion around strategy and tactics and the obvious limitations of my euphoric hopes about the transition in my country. But that immediately makes me recall of your close to the mid-eighties visit in Johannesburg and Durban where you uttered a peculiar word that had us flummoxed: eMail! Little did we know that our admiration for the fax machine would be outpaced by that, other s/heMail. You had a defining influence on many of us trying to fathom out the intricacies of class, race, caste and gender and we in turn, did torture our students with your intermediary class locations (and later, with many more). Your posts are moving and heartening- and your words a counsel about facing the inevitability that will outlast us all. Shwele as we say here!

Astrid and I are at the moment sitting here in Cape Town thinking of you, staring at a full moon on this summer's night and want to say: thank you. Here: to the imagination and to real utopias!

—Ari Sitas, January 20, 2019

Dear Eric,

Your blog was forwarded to me by my son, who is now a grad student in comparative politics, but many years ago, had the pleasure of playing some kind of crazy chess with you when we were in Costa Rica together for a MacArthur Foundation research group. Even these many years later, he remembers your kindness. And of course, I remember your impact as a scholar and activist. Those of us working in other institutions tried for many years to pry you from UW, but it was impossible given your loyalty to your students, colleagues, and to that grand public institution. They have been so fortunate to have you.

Most of all, I appreciate your relentless good will and even optimism about the possibilities of life and the redemption we might be able to expect some day even in a society so plagued by inequality, racial antagonism, and class hostility. To be able to see past all of this into a future that could be better is a special gift. It will be missed.

I hope these last weeks will be filled with the gratitude of hundreds of people who have been touched by your writing and your teaching. Your grace under the most unimaginable difficulty is something to behold.

Our thoughts are with you,  
Katherine

—Katherine Newman, January 20, 2019

Dear Erik,

Like so many others, I am eternally grateful for the ways that you have both directly and indirectly shaped my thinking and the trajectory of my work, and the ways that your work has made possible a more rigorous engagement with Marxist thought. In our brief meetings, in regularly revisiting your writing, and perhaps most significantly, in listening to your recorded course lectures, I have learned much and been forced to systematize my own approach to research that contributes to social movements.

I'm in the middle of a road trip across the South, trying to answer some preliminary practical questions related to my research, and I have been re-listening to your Soc621 lectures, this time starting from the first class and listening all the way through, rather than cherry picking the lectures that pertain to the particular questions I'm

studying at the moment (as I've done in the past). As always, the rigor in understanding class concepts is so insightful and useful, and the focus on ideology/mystification/hegemony in this latest iteration of the class has been especially engaging.

These short reflections don't touch the magnitude of your impact, obviously, but I feel the depth of your contributions in my life and work, and in the outpouring of affection from so many others on this blog and so many other forums. I'll never forget your incredibly kind call to let me know that I was accepted to the program in Madison, the first moment I felt it was possible for an organizer like me to find kindred spirits in graduate school.

Thank you for all that you are and all that you do.

My very best,  
Rishi

*—Rishi Awatramani, January 20, 2019*

Dear Erik

Many thanks for your wonderful blog (received courtesy of Patrick Bond). You have inspired us to the end. A good death, like yours, is a product of a good life; one without regrets, without lament for lack of courage; that has been principled and committed and made a difference. You certainly made a difference to me and many others too; not just those of us from the generation of 68, but to those who are younger, some here in South Africa, who are angry about the savagery that capitalism has inflicted on humanity, and determined to piece together, calmly and rationally, an alternative way, a just and egalitarian way, of organising society. In order to achieve this, we need critical Marxism of the kind you epitomise, and from my travels it is apparent that a small yet growing number of activists and students are reaching this conclusion.

You are one of the cleverest, most knowledgeable people I have ever met, and your writings and talks have motivated me to work harder and think more clearly. But yours has been an intellectual life that eschews intellectualism, that recognises the limitations of intellectuals, and that underscores the importance of mass movements, both in formulating key theoretical questions, and in answering the violations and systemic abuse of ordinary people, especially those who are working-class and poor. I highlighted the following line from your blog: "without being embedded in a social milieu where those ideas were debated and linked in both sensible and misguided ways to social movements, I would never have been able to pursue this particular set of ideas [i.e. Marxism]."

You have also stimulated me and my colleagues through your kindness. We will never forget the way you supported our research on "class" in Soweto. Our 2007 "kombi seminar" in the township, which paused to look around and listen to people, then halted again for us to engage with your generalisations and new questions, is forever etched in my memory, and, whenever recalled, brings a broad smile. Your generous response to our book and Mosa Phadi's film gave further encouragement.

I share your rejection of beliefs about an afterlife, but when people make a difference to the lives of others, a bit of them lives on, it becomes part of the identity and intellect of another human being. This is the reality of living within society. We are too frail to gain lasting benefit from all around us, but we embody the lives of a few - our parents, our loved ones, and, very occasionally, others who influenced our lives in meaningful ways. For me you are one of those very rare individuals, somebody who changed, improved, the way I act on the world. Ngiyabonga. I thank you, comrade. When you leave us, go well! Hamba kahle!

Peter Alexander, now known as Kate.

P.S. I have emailed a photograph from our tour of Soweto that captures the magic of realism.

Professor K. Alexander. South African Research Chair in Social Change, Director: Centre for Social Change, and Professor of Sociology, Faculty of Humanities, University of Johannesburg.

*—Kate Alexander, January 20, 2019*

Dear Erik, I have read your recent posts with great admiration. As so many others have said, you inspire us all in so many ways.

This week, the prize winning poet, Mary Oliver, passed away. Looking ahead to her own death, Oliver wrote in one of her poems:

"When it's over, I want to say all my life  
I was a bride married to amazement.  
I was the bridegroom, taking  
the world into my arms.  
When it's over, I don't want to wonder  
if I have made of my life something particular, and real.  
I don't want to find myself sighing and frightened,  
or full of argument.  
I don't want to end up simply having visited this world."

Erik, I cannot think of anyone who has embraced life in all its aspects more fully than you have.  
May your path forward be comfortable and surrounded by love.

With gratitude, Cindy

*—Cindy Costello, January 20, 2019*

Erik, in all that you do, in how you live, relate to others, and reflect on it all in these blog posts, you continue to be my teacher and mentor. I'm grateful for everything I keep learning from you. Sending love and hugs, Ofer

*—Ofer sharone, January 20, 2019*

Dear Erik.

I am very grateful for the intellectual contribution you have made. In the sociology degree and in the master's degree at the University of Chile, we have read your texts and they are very significant. A hug and best wishes

—Pablo Bivort, January 20, 2019

Dear Erik, I found these wonderful photos of you in Full Utopian Modality on my phone. You're as inspirational as always...

<https://photos.app.goo.gl/tK1tYnvtVrdeEgat5>

—Margaret Somers, January 20, 2019

Dear Erik, Thank you for inspiring a whole generation with your work, your take on the world and of course, your actions...THANKS!

—Zaheer Baber, January 20, 2019

I will always remember attending your lecture on class at the Rosa Luxemburg Center in Berlin. Your explanation of the concepts were so clear and concise and it was a treat to hang out with you and the other attendees afterwards. Best wishes to you and your family.

—Scott Riegel, January 20, 2019

Thank you. My brother passed away last year in similar circumstances. Your words have been very soothing for me. The night he passed Mars was very bright in the sky and that planet shone over my car as I left the hospital for the last time. I remember him now whenever I see the stars and I understand that this is the fate of us all. He was peaceful and with the people he loved. May you be too.

—Karen Evans, January 20, 2019

Dearest Erik:

Over the past few days, I have been thinking a lot about your wonderful reflections on kindness and generosity; on both of these virtues you are one of a kind. You are genuinely inspirational as a teacher: everyone who has ever studied with you experiences first hand your commitment to your students, when we get comments from you on our papers that sometime exceed the length of the paper itself; all typed out on the margins in a relentlessly constructive and cheerful manner. As a critic, you have an exceptionally vigorous analytical mind and students can send you any paper and discover every flaw in a argument. As an interlocutor, you have always been the kindest and most generous, graciously extending your hand to be a source of unstinting support and encouragement.

I cannot thank you enough for what you have given me, and I will spend a lifetime aspiring to your combination of moral commitment and scholarly vigor. You have lived beautifully, and I am only one of countless lives you

have forever touched. I cannot adequately stress that how much I treasure being your student and how much I love you -

Sending you and Marcia all the love I have -

Yours,  
Masoud

—*Masoud Movahed, January 20, 2019*

Dear Erik,

I still wish this were not true... but your amazing attitude is - as everything about you - so inspirational for all of us who have had the fortune to know you! Thank you so much for being you!

There is an old Chinese aphorism that says: "All people must die, but some deaths are lighter than a feather, while others heavier than the mountain." Yours is definitely the last type. It will leave a hole bigger than a mountain in my heart. You, and everything you've ever said and done, everything you represent, will always be with me. You will always be my role model as a sociologist and as a human being. I will always hold my self to your standards. Until we meet again eventually.

With all the love I have,  
Siying

—*Siying Fu, January 20, 2019*

Dear Erik,

Your mindful way of respecting the amazing experience of Life, and sharing with us, are true gifts. If your molecules are just stardust, your soul is a brilliant sun with a huge heart in the middle. Your consciousness is a flawless carefully cut diamond radiating the many colours of the rainbow. Love to you and thank you so much.

—*Jacqueline Martin, January 21, 2019*

Querido Erik,

Te escribo desde Chile para agradecerte tus enseñanzas de vida. Un abrazo grande para ti y tu familia de una admiradora lejana.

Soledad

—*Soledad Parada, January 21, 2019*

I am just a regular person that has always appreciate your work. My mother in law passed away just a couple weeks ago from cancer. We rode out her final weeks with her. I can say from her experience that you are approaching the end with courage. You leave a wonderful legacy and exit with a revitalized socialist movement brewing. Who knows where that will go but you most certainly contributed to this re-engagement with Marxism. Solidarity and Safe journeys!

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—Josh Legere, January 21, 2019

These entries are so moving. I admire your clarity and eloquence so much. Thank you for these, and for the rest of your enormously productive life.

—Doug Henwood, January 21, 2019

You are the best inspiration and role model a leftist and humanist aspiring person can have. The world will be worse off without you, but we will keep reminding it about your brave and sharp thinking! <3 From Stockholm sweden

—Nazem Tahvilzadeh, January 21, 2019

I of course thank you for being that kind of intellectual, writing, engaged stardust you have been for a long life. But I also thank you very much for writing about life as it is when the end is - well I don't know, near? Or just apparent? These words have a specific quality for me, who might not have understood what this will eventually mean, to us all. Thank you, from Gothenburg, Sweden.

—Ann Ighe, January 21, 2019

Dear Erik,

The news about your illness shocked and moved me. I only spent some months in Madison, where I joint your Class Analysis seminar. It was the fall of 2006. And then we met again in the two-week Real Utopias seminar you gave the following year in Berkeley, where I did another short-term visiting stay. But the mark you have left on me is immense.

Since I read the post where you announced the closeness of the end, I have mulled over that: how is it possible that the misfortune of someone with whom you have had little personal contact affects you so much? Reading your blog posts and comments has allowed me to feel part of a wider community of people who have had the good fortune to have met you, even if it was only fleetingly.

I have been reflecting on your great influence in my life, reviewing its track in the stuff that I have written (or planned to write), but also in my teaching work, where there are always shmoo, interrogations, 2x2 tables and the great advice of your mother with which you opened Classes.

However, beyond the deep influence of your ideas or arguments (and the pleasure I have always obtained by reading them), what has marked me forever is your intellectual honesty –that requires us to confront the best arguments of our adversaries and to acknowledge the limits of our reasons and evidence–, as well as your kindness and generosity –even if they were effortless!– with other colleagues and students, including a shy Spanish visiting student with a rudimentary English.

The Real Utopias project embodied these facets: it represents a refreshing, realistic and hopeful way of raising

the prospects for socialism in our time. But, above all, it invites us to face reality with intellectual honesty and strategic debates without political sectarianism.

The enthusiasm, the brightness and the love that gave off what you did has always been an inspiration.

The moving wisdom with which you face these weeks is another lesson, not only to deal with death but also with our lives. We will miss you, compañero, but your echo will resound for a long time.

Un abrazo fuerte from Madrid.

—Jorge Sola, January 21, 2019

Erik, I'd just like you to know that I'm going to talk to my Sociology class about you tomorrow, and say to them that if everyone read writers like yourself the world would be a better place, and read a passage from *The Sociological Imagination*

Ian

—Ian Stone, January 21, 2019

Dear Erik,

Words cannot express the unbearable grief I feel in my heart. Borrowing a poet's words,

Of the moon  
all that's left is a stain upon the window

Of all the waters in the world  
this single drop on my cheek

Thanks for everything, Erik!

Warmest,  
Maryam

—Maryam Ahmadi, January 21, 2019

I still recall the excitement reading *Class Crisis & the State* with friends during my time in the late 70's at Ohio State. Years later it figures you would again rise to the challenge in this final chapter. May we all be as strong as you...

—Jeff Jones, January 21, 2019

Dear Professor Wright,

I have not met you face to face but I have met you in your papers and books many and many times. Right now

in front of me are three books you wrote. I am deeply saddened to read about your health condition. I would like to let you know that you and your family are in the thoughts of many and many people, people you know and people you do not know. Hug! Hug!

—Lijun Song, January 21, 2019

Dear Erik. You're critical and at the same time optimistic Marxism has shaped many of us. In Sweden, the Left Party, as well as the Young Left, class analyses is to a huge extent influenced by your. Your class analyses has therefore been debated all over the country, in all from small basement where young activist first encounter the world of Marxism, and are given a language for things they have felt, to congresses, where we have tried to explore how your class analyses can be combined with an analyses of racism and patriarchy. We thank you, for creating theories that have we could translate to politics, and analyses of the everyday of capitalism.

We will continue the struggle for the real utopias, and the right for all to share and experience them.

The spirit of your work, enthusiasm for life and optimism will be with us.

—paula mulinari, January 22, 2019

Thank you Erik.

—Youbin Kang, January 22, 2019

A friend of mine shared this post with me, knowing that I had been an undergraduate student of yours back in 1991, when I talked my way into your year-long Marxist Sociology grad seminar (team taught with Joel Rogers). My friend knew this fact about me because I spoke of that class often, as it was so crucial to my own intellectual and political development. I am now teaching seminars on Marxist theory myself (Marxist literary and cultural theory, as I ended up becoming an English professor). I don't know what else to say; I just wanted to offer you another data point indicating how successful your writing and teaching have been in extending and expanding the liberatory power of Marxist thought and practice. I consider myself tremendously lucky to have spent time learning from and with you.

—Derek Nystrom, January 22, 2019

## On the Art of Goofiness

January 21, 2019



Recent blogs have been pretty heavy, understandably. I'm in the last days of my life. That kind of focuses the mind around the biggest questions. And that's been combined with some health crises that had such powerful physical impact on me that I needed to share that as well. So while I hope the spirit of these blogs is not just relentless gloom and doom, they have certainly not been lighthearted. Now, so you can get a fuller picture of what my life is like, even in the midst of this, I thought I would share with you the section of the letter to my grandchildren that Becky and I have just completed, Becky typing and me dictating. This is a section of my letter to my grandchildren that describes an extremely salient aspect of my relationship to my children while they were growing up. Which is to cultivate a kind of goofiness, silliness, joking around, a playfulness that pops up sometimes unexpectedly and takes many different forms. Some of this goofiness in a way milder forms I carry into seminars sometimes or other activities with students. but it was away more intense when it was goofiness with my kids. one aspect of this goofiness was storytelling. now my stories weren't always goofy, they weren't always pure silliness, but I would say silliness played a part in nearly all the stories I'd tell my kids. I much preferred telling them stories to reading them stories. so what follows is an excerpt of my letter to my grandchildren, which contains some general discussion of goofiness as a thing we do together. and, in particular, the problem of how you tell spontaneous stories that are free flowing and come easily so it's not work on the part of the parent, it's fun. and the key to this is what I would call creating a gimmick, which is what I would call a story-telling machine. you get a good gimmick, you get a gimmick in your head, and the gimmick basically tells the story. the stories don't need plots, they just need a structure that's funny and enjoyable. And a really good gimmick invites the kids to jump in, put their ideas into the fray, and contribute story ideas and little things that they want to see happen. well, enough introduction. Let's go to the excerpt.

#### Excerpt of letter to my grandchildren

Goofiness as part of a way of life was really important to me and to my relationship with my children. Now, goofiness takes lots of different forms: there's many ways to be goofy. A closely related term is silly. It means having, as part of your way of life, something to counter the dead seriousness of our human condition, to make life fun and funny and not to take everything so seriously. And, for me, the idea of being silly as one of the ways you live in the world has always been an important way of expressing that need. I do take the world very seriously, I've devoted my career to social justice research and to mentoring my students and to being a loving and active father. That's serious business. That's taking the way of life as something important, and you have to devote attention to it. But there's so much that's hard in the world and difficult, and as you get older you get more aware of the difficulties, if you're in our particular privilege condition where children can be shielded from some of the difficulties. So goofiness for me has always been a way of lightening things up. It doesn't mean "don't be so serious," it means, "in addition to being serious, have a lighthearted view of life as well as a serious one."

So one way I express my goofiness is by telling goofy stories, but there were other ways. I think one that was sort of close to telling stories is that I would drive the kids to school through a wonderful little drive called the Edgewood Pleasure Drive, kind of a wooded drive on the way to Wingra School, and we would drive along this road which was canopied with trees, probably about a half a mile all together, and I would pretend that there were dinosaurs leaping out at us. I would drive at about 10-15 miles an hour and when a dinosaur would leap out, I would slam on the breaks, just abrupt stop, so everyone would jerk forward. I did it in a way that was safe--the kids were all buckled up--and clearly not at a pace that would cause neck problems or anything like

that (at least I hope my judgment was good enough.) It would make the drive to school hilarious; I could get everyone in the car just completely cracked up with the fun of imagining there were dinosaurs leaping out at us. And it became very participatory, the kids would yell, “Oh, there’s a dinosaur!” and I would slam on the breaks.

Or if we were having a dinner party, I would slip the lid of some pan under my shirt and take a wooden spoon and give myself a whack in the tummy and make a resounding noise and get the kids to just crack up. And I’d do that unexpectedly, it wouldn’t be part of a game, I could get myself set up and just whack. That was goofiness.

But I would say that one of the most important goofinesses was telling stories. They would be fun to listen to, and as the kids got older, they’d become more participatory and hilarious because of their contribution to the goofiness. Well, people would often marvel at how well I tell stories--I don’t plan them out, I can just tell them--but the key to my way of telling stories that makes it easy to tell a funny story is to have a kind of gimmick, a basic idea about some device that generates the goofiness of the story. The story doesn’t actually go anywhere--there are almost no plots to any of my stories, things happen, but they’re just kind of random and the kids just throw in their own randomness--but if you’ve got a good gimmick, the stories just kind of tell themselves. So I had several of these. The earliest were stories that came to be known as the Josie and Jessica stories. And the basic gimmick was that these two kids were buddies, and that Josie could turn himself into any animal he wanted, but it would only last a half hour and then he would turn back to Josie; and he couldn’t turn himself into the same animal twice in a row, and if he did it too many times in a day, he would get stuck for 24 hours. Which would create problems. If you’re playing as a gorilla and you get stuck as a gorilla, and then you have to figure out how to live as a gorilla for a day. So they would have various adventures, always around getting stuck, that is where the adventure would start.

When I had a good gimmick, I could basically tell a good story in my sleep. So we would be on a long road trip, I’d be driving and I could basically tell a good Josie and Jessica story, I didn’t have to plan it out. Or another gimmick was the search in the high sierras for the McMurtry Mine. Or our endless treks through the jungle on the Road to Mandalay, where Sam was always relegated to a donkey named Slow Poke and everybody else got to announce what animal they were riding. Sam was just enough older than the other kids that I could tease him, he would be the butt of jokes, and he would realize it was part of the fun. If you have a ten-year-old and a five-year-old and you’re telling a story to both of them, you can have the adventure be that they’re riding through a jungle and the little kids get to announce their animals and Sam would always be on Slow Poke; and Sam would take the tease and be fully part of the fun of it, just enough older to realize that this made the whole thing sillier and it wasn’t that he was relegated to some lesser role.

Sometimes I would record these stories. The full set of Josie and Jessica stories and many of the Blizzard Epics and the search for the McMurtry Mines, they’re recorded and you can listen to them, and you can hear your moms yelling out things because I would say something would happen and Becky or Jenny would say, “No, no it didn’t happen like that.” Becky especially at a certain age had a very shrill voice when interrupting my stories. It would just be a kind of shriek. Well, we have recordings of this and you can transport yourself back 30 or 40 years, all of this recorded in the mid 1980s, so a long time ago, and you can see what it was like for me to tell these stories with participation from your moms. One set of these stories, the first set, I actually recorded

when we lived with another family in Berkeley, in the early 1970s, the Zuckers. Now here's a very sweet thing from that set of recorded stories: I recorded those stories, especially Josie and Jessica and the Gorilla. Jonathan Zucker, who was not born when these stories were recorded, he was born in 1974 and I told them to his sister in 1972. Well, Jonathan Zucker had a lot of trouble falling asleep when he was about 6, and his mom and dad thought my recorded story would help him sleep, and it did, it was kind of a magic bullet. He listened to that story, Josie and Jessica and the Gorilla, from around 6 til around 13, so for quite a long time, and he would fall asleep listening to the story. Then when he was a little older, 15 or 16, he became a counselor at a summer camp in Berkeley called Camp Kee Tov. And kids would be sitting around a campfire and Jonathan would tell this story, word for word, exactly how I told it, because he'd listened to it hundreds and hundreds of times, including one part in the recording where I sneezed--and when he got to that part in the story, he would sneeze as well. And to me this is this marvelous human phenomenon. Storytelling around the campfire goes back to ancient times, it's the way religious stories and myths and parables started, it's what's called an oral tradition, not written down, you couldn't put a sneeze in a written down story in the same way, but these stories affirmed the value and sometimes the goofiness of life. Jonathan Zucker would tell the story to the camp Kee Tov kids, and he would sneeze at exactly the place I sneezed twenty years earlier. To me that's a wonderful and deep illustration of the continuity over time of what it means to be human and live together in community and transmit these cultural phenomenon.

Now to really have a story, a child must of course have language. And language kicks in for children at different times; of course, children can understand things before they can speak, but to really tell a story I'd say a child has to be at least 3 years old, and then it really kicks off around four, four and a half, and that's in my experience when a child really gets into the story itself. But I've been thinking about what gimmick I wanted for you. I didn't just want to retell the Josie and Jessica stories to Vernon and Safira, and then Ida when she came along. And I had this basic idea of a world in which everyone is a witch, and they just don't know it. And a witch in this world is someone who has a special power to realize this potential, something they've dreamed about.

So here's the first episode of Safira, Vernon, and Ida: the World's First Tripulo.

Now, you may not know it, but we live in a world where everybody, or at least almost everybody, turns out to be a witch. Now, what's a witch? Witches aren't bad things, they aren't evil, they're just ordinary people who have a special witchly power. They have some sort of power which they might not even know they have. Everyone has a special power, but they might not know they have it, they have to *discover* their special power. Well, this is how it happens: you have to, at some point, say out loud, "oh I wish I could do x" I wish I had the power to do this, to solve this problem, had this skill. Well, if you say this and it's not your special power, nothing happens. If you want to be a great dancer and you're in ballet class at age 10 and you're stumbling about you can't do anything and you say I wish I could be a great dancer and it's *not* your witchly power, nothing happens. But if you happen to say—outloud or in your head—let's say you're having a music lesson and you're stumbling on your violin over a difficult passage and you say, "I wish I could play the violin beautifully, like Itzhak Perlman" and that power happens to be your witchly power, suddenly you have it. Now it turns out that all of the great musicians of the world and all of the great architects and ballerinas and authors, they all had that as their witchly power and at some point longed for it and said it out loud in their heads. And that triggered getting over the hump and activating the power. They still had to put in the effort, to go from a person with

witchly power be a fabulous musician to actually *being* a fabulous musician, but that's how it started off. And that's how witchly powers work for a singulo, a singulo is someone who has the power all on their own. So most people are singulos. And there can be powers that aren't about being a world famous musician, a power could be being a fantastic breadmaker—someone loves making bread, they do it a lot, but it comes out kind of tough, and one day they said, “I wish I could make beautiful bread,” and suddenly you can make beautiful bread like a professional baker.

Mostly the powers that singulos have are good, life-enhancing powers, but they can occasionally be dangerous. You could have a person who says, “god, I really wish I could see through walls,” and that turned out to be their singulo power. Well, that could be used for all sorts of nasty purposes. Or, “I wish I could be super strong and lift up cars.” Well, lifting up cars could be good if someone is trapped under one, but you also could do a lot of damage. But anyway, singulos have isolated individual powers.

Duplos have an added complexity: you can only activate your power if you're touching another duplo who has the same power and you say it at the same time. Well, how likely is that? You could have two duplos who both want to fly, but how likely is it that they're going to bump into each other, be touching and at the same time say, “I wish we could fly.” So there *are* duplos, but very rarely do they discover their powers. And there has *never* been a tripulo, which would be three people who would get together and have the same tripulo power and say it out loud at the same time.

Well, this is a story about three little witches. Fantastic people. Cousins and siblings. The eldest of these witches is a little girl named Safira. She was born in Australia, but comes back to the United States when she's three and a half years old. A live wire, buzzing about in the world, filled with energy and good cheer and fun. She has a cousin named Vernon, five months younger. And then along two years later, two and a half years later, comes the baby of the three named Ida. They don't live in the same town, but they live close enough that they see each other from time to time. Well, the story begins when Safira is about five years old or so and Vernon is four and a half and little Ida is two. One day, visiting in Philadelphia where Vernon lives, Safira and Vernon are playing in the big open living room space in that house. And Safira runs to Vernon and tackles him and they go tumbling to the floor and Safira yells out, “Oh, Vernon! Wouldn't it be fun if we could fly?” and Vernon thinks, “Yeah, that would be really fun,” and they're holding onto each other because Safira had tackled Vernon, and they suddenly lift off the floor together. Whoa. “Whoa, look what happened!” Safira says. They let go of each other, they're at the ceiling of the house, and when you break the connection, the power disappears; you don't get into free fall, it's a gentle dissent and you can guide yourself down. So it's not particularly dangerous, but you have to be holding onto each other, touching—you could be holding hands, holding feet, entangled in some way, but you have to have physical contact for the power to work. So Safira and Vernon are zooming around the house, learning how to do it: it's a skill. They've got the power now, but they have to learn how to accelerate, how to avoid objects, how to move a foot for some directionality, and so forth. They go into the kitchen where their moms are making dinner, and their moms see their children on top of the ceiling and they say, “Whoa, whoa come on down.” They've never seen this before, they've never seen two kids zooming around in the air. So Vernon and Safira let go and drift down to the floor.

Well, you can imagine the moms are pretty concerned. This looks like great fun, but what would happen if you were outside? Would you just go up and up? You could get lost. They had to understand what was going on. So

they went down to the public library in Philadelphia to see if they had any information about people who could fly. And they did find in the corner of the library a little book that said if you wanted to learn about people with special powers you had to go to a library in Edinburgh. So Jenny and Becky went off. Adriano and Mark looked after the children in Philadelphia, and Jenny and Becky got on a plane and flew off to Edinburgh. And they found the book that gave all the information about singulos and duplos. There wasn't much information on duplos, because they're very rare, but they got the basic picture. They went back to Philadelphia and sat the kids down and said, "Look. It turns out that you are a very special kind of person called a duplo. You're young. We don't know how this is going to develop, but let's just set some rules about this. First of all, if you're going to do it, you have to tell us--just don't go willy nilly flying off into the sky, let's just take it slow and always tell us about it. Secondly, we're a little concerned that if you're holding hands and flying high in the sky you might let go without meaning to, and even though it's not dangerous because you don't go into free fall, you could get lost. So we're going to design a set of garments in which you're attached through the garment--so it's by one foot maybe, sweaters or a pair of pants attached at the cuff, but you need to have these special garments if you're going to fly, and let's see if that works, if that's enough of a connection to make sure your powers are activated; it's just a little safer." And they all had a very good discussion. The kids were excited, of course. It was tremendous fun. And then Jenny and Becky said, "The last thing is, we want to go to a safe place where we can practice these skills, where we can really see how these develop and you can figure out how to do it."

Well, time went on, they were five and then they turned six and then they turned seven. And all this time, Ida would tag along but without any special power, she wasn't part of the game. And one day when they were outside at a state park, little Ida came up and said, "Do I have any special powers? You have so much fun, and I get to watch and tag along, but can I play too?" And it occurred to Safira and Vernon that, well, they had never tested it out. They hadn't held on to Ida and said, "Okay, Ida, say outloud, 'I wish I could fly,' and we'll all say it together, maybe she has the same special power." So, they didn't tell their moms and dads that they were going to try this out. They were in a big field. They were wearing a garment where they were attached at the ankles, loose and comfortable, didn't interfere with the fun. They got together, all touching, and Ida said, "Oh, I wish I could fly." And Vernon and Safira said the same thing, "we love that we can fly and wish that Ida could fly with us." And they shot up into the sky like they were rockets. They were turbocharged. They were like airplanes, they could zoom incredibly fast. Vernon and Safira could control their own powers enough as duplos that they immediately put the breaks on. But there they were: the world's first tripulo. Flying around in the sky together was exhilarating. But Ida had no skill yet, she didn't know the rules, and at one point she just let go.

Now remember, letting go isn't dangerous, but in this case it just turned off Ida's power without turning off Safira and Vernon's, because they were still attached to each other. Vernon and Safira could still fly and guide their flight; all that Ida could do was just drift down without any power, like a glider would. Safira and Vernon chased after her, now with diminished power. They wanted to rescue her, but it was a windy day and they lost track of her at one point. Ida drifted down to the side of a kind of cliff, they were in a sort of hilly area, where there was a big tree protruding from the cliff, in which there was a large eagle's nest. And she landed, kerplunk, in the eagles' nest which happened to have three large baby eagles in it. Well, the mama eagle soon arrived and saw this strange bird in her nest. Now you might think the mama eagle would get upset about this and might be aggressive, but no, she was a very sweet mama eagle, bringing back bits of meat for her babies, and she thought, as a gracious host, that she'd feed the new odd eagle with no feathers first. And she tried to stuff this



raw meat down Ida's throat, which Ida really didn't like. So Ida was fussing with this eagle—"Get away from me, stop doing that, no, yuck, I don't want that, ugh"—and finally Vernon and Safira, flying around looking for Ida, spotted her in the eagles nest and they swooped down and rescued her, and continued on their way. They held on to Ida they told Ida, "You can't let go of us." They were going down to the field, next to Lake Michigan where their parents were waiting. "Just stay calm, hold onto us, and we'll make this dissent without any further problems." So they swooped down and ended up back with their moms and dads.

It was a very warm summer day and all the sharks of Lake Michigan were gathered in a big party. This was shark day in Lake Michigan, and it turned out they were gathered right next to where Becky and Jenny and Adriano and Mark were waiting for the threesome to come back. So the threesome lands, and Jenny and Becky especially were very relieved. They were kind of excited to learn that Ida had the same powers that her cousin and sibling have, so that they can be a tripulo, and thought of all the fun things they can do together. Well Ida, when they landed, they were hot, and immediately she jumped into Lake Michigan for a swim, not realizing the lake was full of sharks at that point and the sharks happened to be gathered right where they were. She was a pretty good swimmer for a five-year-old and suddenly she bumped into a shark. These weren't aggressive sharks, they weren't particularly dangerous, but they started playing and flapping around and bumping into each other, and nobody on land knew they were friendly sharks. So Vernon and Safira said, "We've got to get Ida out of there," and they said "To the rescue!" and they jumped into the water as well to rescue Ida from the sharks that she was playing with.

They were in the water, a bit away from shore, and they grabbed Ida, but Ida didn't want to go out. And Ida said to herself, "Wouldn't it be great if I could swim like the sharks." And it just so happened that Vernon and Safira were kind of thinking the same thing, "Wouldn't it be great if we could swim like sharks." They were all holding onto each other and they said it at the same time and whammo! They could swim like sharks. My god, they could swim way better than sharks. They just discovered that their special power was not specifically flying, their special power was that they could do in a supercharged way any form of mobility. They could run like a rabbit. They could hop like kangaroos, they could swim like sharks, they could fly like eagles. They had the super power of mobility. Fancy, exciting mobility. And this opened up a world of play and adventure that would keep them having adventures for years and years to come.

And that's the end of the first episode.

You can see how that's a story generating machine. There'll be different occasions for different problems to arise. The foundation is laid. So I won't be there on a road trip or around a camp fire or at the cottage to pursue this, but maybe the template will survive and other stories will get generated by it.

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So that's the excerpt.

## Mini Medical Update

Mostly I'm feeling fine. No dramatic new developments on the official health front. The only new symptoms are that I had a couple of episodes of gasping for breath, where I simply could not fill my lungs. The episodes lasted maybe 15-20 seconds and were pretty scary. They were triggered by almost no effort, standing up and pivoting, basically. But this is to be expected it. It's one of the things that happens in late stage AML. And I'm okay. I'm okay.

## Comments

Hey Eriki! Great story! I really liked it but I also loved the beginning about Jonathan Zucker ... I never knew about his hearing your story over an over and then retelling it! And thanks for the tip about how to create a story around a gimmick. I've always felt tongue-tied when kids ask for telling (as opposed to reading) stories, but you make it sound easy (it isn't but I appreciate the help!) But most of all it's great to read your blog. We were getting anxious because TWO WHOLE DAYS had passed without a post. Ron and I were telling ourselves that you no doubt have to pour most of your energy into the grandkids' letter, of course. But thanks for this lovely update and lesson in silliness!

—*Mary Jo Maynes, January 21, 2019*

I hear your voice, Erik, as I read the story, and your grandchildren will, too.  
P.S. No gimmick would bestow on me the power to spin a story like you do!

—*Cathy Loeb, January 21, 2019*

Thanks Rik. Great stories, or story generating ideas. Can you give me Canadian rights to the stories? My children are all grown. But I have a three and a half year old grandson, Julian, to tell the stories to. Of course, all he can be is a singulo (since I assume that all characters should be children or grandchildren or at least relatives of the story-teller). For many reasons, I would love to have more grandchildren. Thanks for giving me an additional reason: so that Julian can become a duplo. (or, rare as it is, a tripulo). Carol and I think about you a lot, and hope for the best in the circumstances. Love to you, Marcia, Jenny and Becky. Peter

—*Peter Rosenthal, January 21, 2019*

I remember occasionally carpooling to Wingra and stopping for dinosaurs!  
Also, you are a beautiful person and a wonderful storyteller. Safira, Vernon, and Ida are very lucky to have these stories.

—*Miriam Jacobson, January 21, 2019*

Hi Erik,

Thank you “from the heart” for your beautiful writings in this blog. They add to the beauty of your other writings, talks, and practices of illumination that have enlightened the lives of countless beings like me, even

though (as I've mentioned earlier on this blog) I never have enjoyed the pleasure of meeting you face to face.

Two other brief and probably inadequate expressions of gratitude:

One concerns medicine, public health, health policy, and medical sociology. In the blog you have conveyed mainly positive experiences and relationships with those fields, as painful as some of them have been. For those who spend our working lives in those fields, the day-to-day experiences often become darker, reflecting the dark social realities of capitalist health care, especially in the United States. I'm not sure you realize that you have exerted a profound influence on those of us confronting the reductionism, empiricism, victim blaming, and superficiality in the usual depictions of social class in our fields. Your work has allowed us to construct, still incompletely, ways to theorize and to study social class as a "social determinant" of health. These ways of knowing social class incorporate the Marxist-based approaches that you have created, and your influence continues to grow.

Another gratitude focuses on the utopias project. You are one of the very few people on the planet with the courage and brilliance to confront in a meaningful way the incredibly challenging task of imagining the "transition" from capitalism to post-capitalism. As Jameson and others have said, it's easier to imagine the end of the world than the end of our economic system. Yet, aware of the criticism you would generate, you audaciously have accepted that challenge of imagination. And now, your profound contributions are helping many experiments in building solidarity economies outside capitalism to flourish.

Finally, while your stardust image may help in your own current transition, I would argue that your existence and profound contributions to sentient beings on this fragile planet do have another meanings as well. One of these meanings has to do, I think, with the evolution of "mutual aid" (to use Kropotkin's persuasive term) and consciousness about its importance – a principle you have embodied throughout your years among us.

Thank you, Erik, again... from the heart.

Howard Waitzkin

*—Howard Waitzkin, January 22, 2019*

Erik, your situation is "heavy" for sure, but your blog has captured your spirit, which is so full--still and despite all--of optimism, generosity, love, brilliance, and, yes, some goofiness! Your last days resonate with all the many days I've known you; you remain an inspiration to us all, a model of how to live life and how to leave it.

I wish I could be there to give you a very big hug!

With lots of love and admiration,  
Margaret

*—Margaret Levi, January 22, 2019*



Erik, I think you wrote profound and beautiful metaphores in The Art of Goufiness. I really enjoyed reading them. Everything in it. Thank-You so much. Obviously, you are a great story-teller and it is a yoy to read you, as well. Great that you thought of dictating all that to Becky. Letter to your grandchildren is a text exploding with imagination and vividness, and, besides, you also give us the analitical clues to create stories, what you call a "story-telling machine". Duplos, Singulos and Tripulos. that's all we are, after all. Witchs who become so, when our to desire to be something in life is so strong and our effor to achieve it follows. That is our power. I also enjoyed reading your car journey to school every morning running into dinosaurs!! What a great parenting, Erik. Your children must be so proud. I think I will enjoy translating to Spanish your Art of Goufiness". It is a Masterpiece.

Much much love, Erik. It is astonishing that you can be writing this at this very moment. You are lucid and analytical and subtle and humourous and clever, smart, intelligent. And, then, you decided to put all that battery to the service of a good man fighting for the best posible cause.  
Natalia

*—Natalia García-Pardo, January 22, 2019*

I forgot to give you and Marcia a big hug, And also to wish you peaceful moments.

Natalia

*—Natalia García-Pardo, January 22, 2019*

So Erik, I have a burning question about your lovely story, which I thank you for sharing with all of us as well as with your grandkids. Why Edinburgh?

This particular post is such a good illustration of how in the many years I have had the good fortune to know you, I often have thought about how you are simultaneously very serious and quite goofy. And the goofiness (along with your kindness and generosity) explains why so many of us out here love you as well as respect and admire you. That, plus the fact that that you can always manage to include one more -- one more student, one more colleague, one more .friend.

I have been spending the day writing something about negative partisanship and increased affective party polarization and it occurs to me that it wouldn't be a bad thing to inject a bit more goofiness into the very serious terrain of partisan politics. Maybe there would/could be less hate attached to a political party or political figures that oppose one's own views if those persons could be capable of and exhibit some goofiness in appropriate contexts. Or maybe we don't have enough contexts in which this is considered appropriate.

I'm not saying we shouldn't do everything we can to oppose and reverse policies we consider unjust, and I'm not saying we shouldn't get very angry about all the serious injustices out there in the world, but I'd certainly rather there were less hate and vitriol directed at persons...

Hugs,

Robin

—Robin Stryker, January 22, 2019

Dear Erik, these are magical words: "Everyone has a special power, but they might not know they have it, they have to discover their special power." How blessed your children were to have learned this from their marvelous dad, and for your grandchildren to learn this from your wonderful daughters, who learned it from their marvelous--generous, kind, and a brilliant story-telling creature--dad...

Your stardust of beingness--The Beingness of Stardust?--is a lesson and a comfort to anyone who's come close, and knows it's coming soon, to the end of our own stardusthood. I never knew I was stardust until you explained it to us in your own case, and now you have changed our understanding of facing death and facing the fear that some of us--though not you--are still burdened by in thinking about it.

I thank you deeply for your bringing the inevitability of death out of the darkness of suppressed thoughts and fears, a place that colleagues and intellectuals rarely (if ever) venture onto with each other (in what seminar on political economy would that arise in the course of things?). This is a remarkable gift to all of your devoted friends and blog readers, all of whom will face--sooner or later, with or without warning--what you're dealing with, yet now we have your words to hang on to to give us strength and even perhaps some degree of fearlessness, knowing that we have your inspiration to guide us--with so much grace, matter of factness, and humility.

No wonder you have graced so many of our lives--you were all along carrying a surfeit of it, enhanced by a stardust-encrusted brilliance that made so many want to learn from you; not just knowledge but something more that perhaps couldn't be fully understood until now that we have the privilege of being in your presence as you reflect on your own history of beingness.

Thank you, dear Erik...May you continue to thrive and blossom as you think through and share with us these remarkable reflections, and may we be lucky enough to continue to benefit from them for as long as possible.

And may you continue to be "Okay" and let us know that "I'm okay"...

Enormous hugs to you and Marcia and your extended family.

Love Peggy

—Margaret Somers, January 22, 2019

p.s. You've inspired me to continue to try to \*discover\* my special power....

—Margaret Somers, January 22, 2019

Stories live on forever. Your stories especially, dear Erik. Important and scholarly stories, as well as the goofy ones. I loved reading about the fate of the Josie and Jessica stories - how they how they evolved from being silly stories being told at home to helping a young man fall asleep at night, only to find their way to campers sitting around the campfire. The power of a great story. This is the power that you have given to us - with your lectures and with your blog. Thank you, Erik. You are an extraordinary storyteller.

—Szonja (Szelényi) Ivester, January 22, 2019

Thank you so much for sharing, Erik. I'm looking forward to the next episode.

—Ruy Braga, January 22, 2019

Erik -- rest in power. I can't thank you enough. A luta continúa wherever you are, inside all of our hearts and in the stars. A passing weightier than Mt. Tai. We love you.

—Griffin McCarthy-Bur, January 23, 2019

Goodbye, my dear Erik! Your beautiful smile will be dearly missed, but your intellectual legacy and above all, your moral commitment, will live forever. You have touched countless lives during your beautiful life and brilliant career. I cannot stress enough that how much I love you -

—Masoud Movahed, January 23, 2019

Very sad to learn of your passing on, dear Erik. Many warm and cozy memories of ... you being goofy with my two children when they were little, and then consulting with them about political strategy as young adults. You playing your violin for lively dancing at my 40th birthday and giving me thoughtful advice on my applied research. You being a loving supportive husband respectful of a smart wonderful wife over time...over time. Wishing you had had more time. You had amazing super powers, Erik!! We wish you had had more time.

—Lynn McDonald, January 24, 2019

## Love and Sorrow

January 23, 2019

Hi everyone,

This is Becky writing.

Erik died just after midnight last night.

Marcia, Jenny, Michael Burawoy and I were all there with him. Yesterday morning, he had a fever and complained of pain; and things moved very quickly to a point where he was not able to be responsive. We did what we could to make him comfortable, and the nurses and doctors at Froedtert were helpful, compassionate, and supportive. We spent time during the day and evening together reminiscing and laughing and holding his hand. We talked about how he would have had so much fun being there with all of us. Marcia finished reading

him The Clearing so he could hear the ending. We believe he was peaceful at the end.

We know how much this Caringbridge site has meant to him over the past months, and the community that has formed here is truly remarkable. It's been a great source of comfort and inspiration to read the comments here. We are grateful for these ways that we get to continue to experience his great love of people, life, and the world. Thank you for being a part of that.

## Comments

My condolences to all. I didn't know Eric, but my friends who did thought the world of him, and his work was so valuable.

—Doug Henwood, January 23, 2019

Göran and I are so very sorry for your loss, our loss.

—Marianne Ahrne, January 23, 2019

My sincere condolences to the family about the tragic loss of your beloved husband, father and grandfather. The world will remember Eric as a great person and his works will continue to shape young students and activists' understanding of class and their praxis.

—Christian Fuchs, January 23, 2019

All my love to you all. Erik was always loved and is already missed...

—João Peschanski, January 23, 2019

:( condolences to all of you. He was such a great person. Love and peace, Erik.

—Samer Alatout, January 23, 2019

We will really miss him.

—Elizabeth Wrigley-Field, January 23, 2019

Sending so much love to all of you.

—Gay Seidman, January 23, 2019

We have such fond memories of you all from YSP days. Tom and I are sad to know of Erik's illness and death. You have our condolences.

janet and tom pugh

—*Janet Pugh, January 23, 2019*

Sending love and peace.

—*SARAH S, January 23, 2019*

A strong sadness and a deep admiration for what Erik did all his life and for his lucid courage during the last days.

—*Fabien Tarrit, January 23, 2019*

Dear Becky,

Thank you for your beautiful words of connectedness in this time of grief. My heart is so full, thinking about you all, Erik's wonderful family, and closest friends. And Erik himself of course, who meant so much to so many. I daresay that his ever-deepening writings on this blog have changed many of our lives in ways we sense but can't fully articulate. I know they have mine. Love to all of you, Julia

—*Julia Adams, January 23, 2019*

Thank you for sharing. So glad you were all together.

—*Spencer Wood, January 23, 2019*

Dearest Becky, Jenny and Marcia

Such sad news on the Caring Bridge site which has been such a window into Erik's life and extraordinary mind and heart. From his musings about stardust and his place in the universe to the funny stories from his memoir, his willingness to share his most private thoughts and hopes, I have looked forward to his presence. I shall miss him. My love and condolences. Bobbue

—*Barbara Marwell, January 23, 2019*

Much love. Xo

—*Heather Crowley, January 23, 2019*

So much love to everyone. Thinking of you and cherishing the time we had with such a remarkable person.

—*Josh Wright, January 23, 2019*

My sincerest condolences to Marcia and the rest of his family and closest friends. He leaves a big hole in the life of the department he loved so much as well as in the hearts of his colleagues and students. This blog has

been a gesture of his great love and deep thoughtfulness and I feel privileged to have shared this way in his processing of his experiences, past and present. Sending gratitude and affection to you all in return, and thanks for the stardust Erik shared throughout his life. Hugs and sympathy to all of his nearest and dearest.

—Myra Ferree, January 23, 2019

My deepest condolences .  
Darrel Moellendorf

—Darrel Moellendorf, January 23, 2019

Sending much love.

We are glad that at least we have been able to be with Erik through this blog. We both feel we've grown and come to know Erik even better day after day. --Sandy and Jenny

—jane mansbridge, January 23, 2019

Our hearts are with you, Marcia, Becky, and Jenny, as we feel with you this great loss. Erik was lucky to have you all in his life, and you fortunate to have him. We send much love,  
Judy and Lewis

—Judith Leavitt, January 23, 2019

Thank you for sharing with all of us who have followed Eric these past months. Putting your own lives on hold for his was a great gift as any parent knows. I think we all would like to be able to write the most amazing stories the day before we die, but of course we would like to have had even more. It's 9 pm in Stockholm. Candles in the window, thinking of Eric's and your courage and grace. Betty

—Elizabeth Thomson, January 23, 2019

Condolences to all of you. Erik gave the world his gifts to the very end.

—Shireen Hassim, January 23, 2019

Condolences to all of you. Erik gave the world his gifts to the very end.

—Shireen Hassim, January 23, 2019

Sadness is immense, but so is our gratitude for all Erik did. Love to all!

—Daniel Bin, January 23, 2019

Dan and I send our heartfelt condolences. We will miss his cheery wave and white curls peeking out from

beneath his helmet as he cycles by.

—Naomi Chesler, January 23, 2019

May his memory be a blessing. So much of this blog has been a lesson on how to live and to love. Judy and I send our love to you and your family and to the extended network of people whom Erik loved, nurtured and inspired..

—Lewis Leavitt, January 23, 2019

Holding you all in the Light. Margaret

—Margaret Vitullo, January 23, 2019

Thank you so much Becky. Love to all you Erik's family and friends. Erik meant a lot to me and to so many others. His exceptional ideas and emotions will stay with us and future generations of Marxists , social scientists and more . His research, Marxism, generosity with students,... were all inspired by a great sentiment love of people and social justice. I regret profoundly not having been able to see him recently. Life will not be the same knowing that Erik is not there. But I will try to follow his example. Thank you Erik. Love.

—Carles Muntaner, January 23, 2019

Our deepest condolences to Marcia, Jenny, and Becky and the rest of the family and friends. While Erik prepared us for this moment, it is totally devastating. Erik was and will always be an inspiration to so many that he touched around the world. He last came to South Africa in 2016 and gave seminars and a public lecture to packed audiences and was able to translate complex ideas into our concrete conditions in South Africa. He was even able to make the Schmoo resonate here. We loved his time with us and have so many fond memories with him, amazing food to great plays and music to engaging conversations, and exploring ideas about cooperative economies and pathways beyond capitalism. We learned much from him: class analysis, real and unreal utopias, friendship, and solidarity, which will remain with us for always. We will miss him deeply. With much love to Erik and his family,  
Michelle and Vish

—Michelle Williams, January 23, 2019

Sadness, respect and love.

—Haris Golemis, January 23, 2019

Sharing your sorrow..So sad, yet such a meaningful life. After the entires in this blog, Eric will live in our minds not only as a great Marxist scholar but also such a gentle and courageous person. Our love and condolences.

—*?ebnem O?uz, January 23, 2019*

He will be missed terribly. I have learned so much from him, his work, and how he approached life. And I expect to learn much more, still. But I never knew that I'd learn just as much from the gracious, thoughtful, and love-filled way he approached his death. Lots of love to you and yours.

—*Adaner Usmani, January 23, 2019*

Oh, Becky. Sending love and light your way and holding you and your family in my heart. His memory will be a blessing.

—*Beth Sondel, January 23, 2019*

I'm so sorry. I can't say much more right now. Thank you for your post to us all, Becky, and much love, in sorrow, to you and Jenny and Marcia and your families.

—*Mary Jo Maynes, January 23, 2019*

Condolences to you all and to Michael. Much sadness in Johannesburg. With tears and happy memories. Kate

—*Kate Alexander, January 23, 2019*

So so sorry. Much love to all of you.

—*Michèle Cohen, January 23, 2019*

Erik, and you as a his family, will always be in our hearts. Annelie and Håkon

—*Håkon Leiulfsrud, January 23, 2019*

Thank you. Love to all of you.

—*Hillel Steiner, January 23, 2019*

Dear Marcia, Jenny and Becky,

Rik and you were remarkable in the ways that you faced his death. You've given all of us an extraordinary lesson in how to deal with the ultimate tragedy that awaits all of us and the people we love. Thank you very much!

Love and condolences from Carol, me, and our children.

—*Peter Rosenthal, January 23, 2019*

Our condolences. Erik was a wonderful human being and we miss him. Give Marcia a long hug from me and



Erica (from Stockholm).

—*Stefan Svallfors, January 23, 2019*

This is a terribly sad day. But the inspiration and example that Erik provided through his writings and his life will live on with us for the rest of our lives. He shows us what it is to be a mensch and how one can make a difference. Thank you, Erik.

My deepest condolences, Marcia.  
Love, Bob

This part is from Suzi (Weissman): I only met Erik in Skype calls with Bob, and over the years through his writings. I was immediately taken by Erik's warmth and the power of his friendship. It was in reading the many of Erik's journal entries here that we could see what a true mensch he was, with equal measures of erudition, love and even goofiness. Erik provided us all with an elegance in life and in dying. Deepest sympathies.

—*Robert Brenner, January 23, 2019*

John and I have been thinking about Ricky throughout his journey. We are impressed by his courage and ability to share himself with others. His blog should be made into a book called a travel log of life. Wishing the family our sincerest sympathy.

—*John Posner, January 23, 2019*

A heavy heart, but deep gratitude for friendship over 40 years and for profound connection and teachings of the last 10 months... Love, period.

—*Cathy Loeb, January 23, 2019*

I am sending every ounce of love your way, dear Marcia, Becky and Jenny.

—*Amelie Davidson, January 23, 2019*

We are so sorry to hear this. But you made his last weeks into very fine weeks - and shared both sad and happy moments with all of us, thank you so much for that!

//Lennart & Anne (Lund, Sweden)

—*Lennart Olsson, January 23, 2019*

Marcia, Jenny, Becky, Adriano, Mark,  
Ricky's was a life well lived. His family, friends, students, articles, books, and many who never met him personally will surely carry forward the echos of his conscious stardust.  
The fullest of tear laden condolences,

Wally & Nancy

—Wally Rosenthal, January 23, 2019

My sincerest condolences, Becky. From São Paulo receive the solidarity embrace of my whole family. Erik was a role model for me. Much sadness, but at the same time a deep sense of gratitude for him to have existed. He touched our lives. Thank you.

—Ruy Braga, January 23, 2019

I am so very sorry and I offer you all my condolences. I will miss Erik. I also see how much wonderful support he received from his family and friends and that is so good. I feel very sad.

—Joseph Blasi, January 23, 2019

Marxists and Sociologists everywhere share your grief and relish the time we had together.

—Rich Hogan, January 23, 2019

Dear Becky, Jenny, and Marcia:

With tears in my eyes and deep sorrow in my heart, I read the post above. I am only one among the countless lives Erik has forever touched. He was loved so much and will be dearly missed. His exquisite intellectual legacy and above all, his moral commitment, will live forever.

A warm embrace and much love to all of you -

Yours,  
Masoud

—Masoud Movahed, January 23, 2019

My deepest condolences to all of you. Erik has been such a source of inspiration to so many of us, both through his work and as a human being. He will be dearly missed.

—Barry Eidlin, January 23, 2019

My deepest sympathy to you Becky and to Jenny and Marcia as well. Thank you for having the wherewithal to let all of us know,, and I hope you can take some small comfort in knowing that the love, admiration and respect all of us had for father spills over to embrace the rest of you in your sorrow.

—Robin Stryker, January 23, 2019

Erik's is a wonderful story that you all helped to create. My deepest condolences.

—Lorna Zukas, January 23, 2019

sending love to you all. Erik was an extraordinary person in so many ways, including in these final months.

—Debra Satz, January 23, 2019

deeply saddened, and also tremendously grateful to Erik for giving us all so much. He has been an inspiration these past few months. sharing the sorrow with the family.

—Tod Van Gunten, January 23, 2019

Erik was an inspiration in life and in dying. The human will be missed. The legacy will endure.

—William Roy, January 23, 2019

Dear Becky, Jenny, and Marcia,

I am so, so sorry. I'm at once angry at the universe for taking such a good--no, great--person from us, and appeased since I know Erik was suffering and that he had made his peace with dying, and we were all lucky to receive some of that peace by reading and commenting here on this blog. Thank you for taking the time to transcribe Erik's thoughts and share them. He taught everyone he interacted with, no matter how large or small the engagement, to live with love and with grace. You have done a tremendous job in these last few weeks, and I can't imagine that things are any easier now. I'm sending you all love and support, and I hope some time to convey these feelings in person, as well as introduce our kids (Vernon and Safira are both close in age to my daughter Laila) when we are all next in Madison together.

—Miriam Jacobson, January 23, 2019

This is a terribly sad day. There were so many unanticipated twists and turns in the past few months. But one thing he knew for sure: we all love him dearly and are forever thankful for who he was.

My deepest condolences to Marcia, Jenny and Becky and the rest of family.

—Cressida Lui, January 23, 2019

Oh Marcia, Becky & Jenny. We are feeling great sadness and sending you love and comfort at this difficult time. Thank you for sharing Erik and your family with us through this site.

...May his memory be for a blessing..

warmly, Ron & Cherie and family.

—cherie diamond, January 23, 2019

Warmest thoughts and deep condolences on Erik's passing to Marcia, Becky, and Jenny, and your extended family. One of my best memories at ASA is being his "road buddy" (Erik's term) for the Travels with Erik campus tour in 2012, where we drove nearly 2700 miles together to a host of universities and colleges in the southwest and deep south. They were almost all minority-serving institutions and Erik got some important feedback on his Real Utopias talk which he would give as ASA president at the 2012 ASA Annual Meeting in Denver a few months later. My favorite part of the deep south portion of the travels was sharing a not-so-glamorous rental car with Erik and Marcia, and seeing their devotion to one another and loving partnership up close and personal. I will always admire Erik as a world-renowned scholar and ASA president, but even more so as a husband, parent, grandparent, and good friend to so many. Farewell road buddy and thank you for everything you gave to the discipline of sociology and your students.

—Jean Shin, January 23, 2019

Dear Marcia, Jenny, and Becky,  
My heartfelt condolences to you all. What a lovely person and remarkable human being Erik was.

—Mansoor moaddel, January 23, 2019

I'm so sad for you and the rest of us. Kjell and I send our deepest, heartfelt sympathies to Marcia, Becky, Jenny, grandchildren, and Michael (my first theory prof). My mother here in Hawaii is 94 years old. I wish Erik could have stayed until he was 94. I will miss him, and the department will never be the same.

—Joan Fujimura, January 23, 2019

I am a recent PhD from the sociology department. Truth be told, Erik and I never spoke more than a "Good Morning" or "hello" in the hallway—often as he was wheeling his bike through the hallway of the 8th floor. However when Erik became sick, I learned about his journal here on carebridge and became an active reader as he journeyed through his illness. Through the digital pages, I got to know him. I laughed. I cried. I thought. His words allowed me to know him and his insights into life, Sociology, and everything else was an incredible treasure. As I read about his passing this morning, I feel enormous sadness for the family and friends that he left behind and gratitude to have "known" a great soul like his. May you find peace and comfort in his memory and legacy.

—Gina Longo, January 23, 2019

Dear Marcia, Becky and Jenny, we send you all our love. A big, big hug. Pablo and Vale

—Valeria Galetto, January 23, 2019

Dear Marcia, Becky and Jenny,  
My thoughts are with you. Erik always was a decent, kind and caring person. I all will treasure his human and intellectual qualities.  
Richard Lachmann

—Richard Lachmann, January 23, 2019

My heartfelt condolences. Erik was a beautiful person. I will always cherish the class that I took with him as an early PhD student and to witness firsthand his profound goodness as a person, his brilliance as a scholar, and his generosity as a teacher. He will be sorely missed. Love and big hugs to you and the grandkids; you are all in our thoughts. He was very lucky to have had a wonderful family like yours.

—Sarah Stefanos, January 23, 2019

Erik taught us as well in his blog as he did in his writings.  
In so many ways he is not gone. With the greatest respect for him and deep condolences to your family,  
Howard Winant

—Howard Winant, January 23, 2019

He will be missed :( rip

—Jernej Štromajer, January 23, 2019

I'm thinking of you, Marcia, and of your girls, and wishing a long, continuing river of support from all your friends as you become accustomed to this deep loss.

—Janet laube, January 23, 2019

Erik inspired us throughout his life, and continues to inspire us beyond his passing. Much love.

—Adam Gamoran, January 23, 2019

This is a terrible loss. My deepest condolences to his family, friends, and the many others who were touched by his life and work over so many years. May his memory be for a blessing.

—JoAnn Jaffe, January 23, 2019

Marcia, Becky, and family: So sorry to hear about this loss to you and all of us. I will always remember being in a Border's Bookstore (are there any left?) in Washington, DC, in the mid-90s, and coming across an edited volume entitled *Analytical Marxism*. Within that book was a chapter by Erik called "What is middle about the middle class?" It blew me away. It showed me it was possible to do rigorous social science while staying committed to one's deepest political beliefs. I began to ponder going to graduate school. Eventually, I became one of Erik's students. His works still inspires me to this day.

—Matt Dimick, January 23, 2019

We were very fortunate to host Erik in Florence and enjoy his kindness, sympathy, intelligence, commitment. We will cherish and honour his memory. Love and solidarity to all of you

—*Donatella Della Porta, January 23, 2019*

Becky, I join everyone else in sending my condolences. Eric's was a life well lived. He will be missed by so many.

Katherine.

—*Katherine Newman, January 23, 2019*

Becky, I join everyone else in sending my condolences. Eric's was a life well lived. He will be missed by so many.

Katherine.

—*Katherine Newman, January 23, 2019*

Dear Marcia, Becky, and Jenny,

We join in the outpouring of love and condolences to your whole family. Erik was an inspiration to so many people.

Elliott and Norma Sober

—*Norma Sober, January 23, 2019*

I am so sorry for your loss. Erik was an exceptional person whom I will never forget. It was a pleasure caring for him and getting to know your family. Your family will be in my thoughts and prayers.

—*Kaela Heinrich, January 23, 2019*

I can't even comment here. I had to announce Erik's death to our Board, and to those who loved him so much but were not reading the blog. I only thank the Fate that allowed me to reach Wisconsin in time to say goodbye. A friendship of 47 years, which became closer with each shared field of experiences ... it will never be lost but I do not know how to absorb the void. You know, Marcia, Becky, Jenny, all of you that I am there with you, treasuring the last words he told me, and crying.

—*Magali Larson, January 23, 2019*

Dear Marcia, Becky, and Jenny: our thoughts are with you today on this saddest of days. I am so sad for this loss to all of us, but heartbroken for you as I know how much you all love him. He always spoke about his love to you in unconditional and absolute terms, thank you so much for sharing so much in recent weeks. - gianpaolo

—*gianpaolo baiocchi, January 23, 2019*

Dear Marcia, Becky and Jenny,

A very sad day. Erik was a unique and wonderful person. I will never forget him . He was a wonderful mentor and friend. My heart goes out to all of you. Thank you for sharing these last few weeks with us. Much love and hugs to you all.

Janeen xxxx

*—Janeen Baxter, January 23, 2019*

While expected, it is still a shock. My heart goes out to all of his family and friends. He will be sorely missed but dearly remembered.

My condolences and love,  
Margaret

*—Margaret Levi, January 23, 2019*

Dear Marcia, Becky, Jenny and families. I am so sorry to hear this. Erik was a wonderful man who changed and enriched my life. Please accept my deepest condolences. It is much too soon! With love to all of you. Mark.

*—Mark Western, January 23, 2019*

Dear Marcia, Becky, Jenny and families. I am so sorry to hear this. Erik was a wonderful man who changed and enriched my life. Please accept my deepest condolences. It is much too soon! With love to all of you. Mark.

*—Mark Western, January 23, 2019*

My heart is with all of you. I am so glad that Erik transitioned to stardust clear-eyed, kind, lucid and noble. That's the Erik I know.

*—Ivan Evans, January 23, 2019*

It was such a tremendous honor getting to know Erik and your family during this journey. He was an amazing man and touched so many lives through his own. I am lucky to have been able to laugh and learn with him. You are all in my heart and thoughts.

*—Lexie RN, January 23, 2019*

Very sad. I was a grad student during Erik's early years in Madison. I know what a wonderful reputation he had.

His last comments are a testmanent to courage, grace and wisdom.

My condolences and wish for solace to all who grieve.

Jay

—Jay Brodbar, January 23, 2019

Dear Marcia, Becky, Jenny,

My most sincere condolences for Erik's lost. I wish I could be there to give you comfort. Thank-you so much for telling us that he died peacefully.

So important to know.

Yesterday, I was reading "On the Art of Goofiness", and I was delighted and astonished about everything he said. And, then, some hours later, I believe, he died. Well, he was Erik till the end. Tremendously lucid, and loving and sharing his wisdom with us all.

I send you all my love,

Natalia

—Natalia García-Pardo, January 23, 2019

Dear Marcia, Becky, Jenny and families:

Thank you for letting us know this sad news through Caringbridge, which has sustained us throughout these months.

Erik's voice - in all the marvelous ways he used it, from travel guide to goofy storyteller to loving teacher to dearly beloved person - came through to the final days, part through your transcription or message.

What an amazing creation of stardust he has been.

This is only the beginning of a river of testimony and of support. And his legacy will include the love and courage he demonstrated at the final stage of his life. He taught us to live fulfilling lives and to face our mortality with courage and grace.

We hold you in our hearts.

with tearful gratitude that we knew him,

Beth and Woody

—Beth Wright, January 23, 2019

So sad!

As we all know, Erik was a brilliant scholar but as his vice-president, I learned how great a person he was. I particularly admired his dedication to promoting sociology in many of the most resource poor institutions of higher education across the U.S. when he was president of the American Sociological Association, including colleges that were predominately black, native american and latino. He has set quite an example.

His work was mentioned in a lecture today by Howard Winant before we learned of his passing. And I was about to write him before I saw this.



My deepest condolences and sending love and peace,

Eddie

—Edward Telles, January 23, 2019

Dear Marcia, Becky and Jenny, my deepest condolences to you. Erik went out in his own inimitable style, wringing every bit of insight and humanity out of his ordeal. It's amazing to see just how many lives he touched.

Vivek

—Vivek Chibber, January 23, 2019

His books and then his unflinching look at his ordeal - he made us all better people

—Tarun Bhartiya, January 23, 2019

What a profound loss for all of us. We'll miss you greatly, Erik. We'll miss your voice in the conversation. The conversation will go on, but it will be different without you. You contributed to this world in many ways over many years, and that contribution is still with us.

—Joel Andreas, January 23, 2019

Dear Marcia and Becky and Jenny,

Erik will be so much missed by all of us who worked with him and we have all grown and been inspired by his blog. I have worked with Erik for almost 40 years and he (and Marcia) were among the first people I met when I first visited Madison in 1980. Even though we were not close, I remember Becky and Jenny as little children. And I remember Marcia as a constant warm presence whenever I saw you. But now I wish to give you the special condolences as family as I know that your own loss and grief as wife and children are particular and not the same as that of all of us who knew Erik as colleague or mentor. My heart goes out to you. I am a religious person so I will say that my prayers are with you. I also heard that you recently lost Marcia's father as well and I add my condolences on that loss. May you find comfort and care from each other and from all the people around you.

Pam

—Pamela Oliver, January 23, 2019

Dear Marcia, Jenny, and Becky,

It is said that "you die as you live." Erik's blog --- and his journey to death --- echoed his life in many ways. He offered a witty, clear-eyed analysis of his situation. He wrote beautiful, calm, and thoughtful analyses of his situation. And, in the process, he also helped to bring people together --- and help all of \*us\* --- as we began the grief process over his impending death.

We will miss him.  
I am thinking of you in this sad time.  
Annette

—Annette L., January 23, 2019

Dear Marcia, Becky, and Jenny, Rob and I thank you for sharing these months with all of us. We have followed Erik's blog and learned from him here as we have so many other times in person, in his work, and in the way he lived his life. We honor his memory. With our deepest condolences. Judy

—Judith Seltzer, January 23, 2019

He leaves an extraordinary legacy -- his family, his books, his friends, this journal... As Eve said to me about Bob, he died as he lived, with love and with deep intellectual joy. These are difficult times, and I grieve for Marcia and all the family. My love and my heart goes out to you all.

—Martin Goldstein, January 23, 2019

Bye, my wonderful teacher, Erik. Thanks to your efforts, we will have more and more Real Utopias which we desperately need. You will be missed for ever. Hasta siempre, Maestro.  
- your student Donmoon

—Donmoon Cho, January 23, 2019

The first time I met Erik was in my Scholar Activism class at the University of Wisconsin Madison. He was a visiting scholar to our class. He was a person of great kindness and extraordinary talents. He will be missed.

—Anthony Hernandez, January 23, 2019

Dear Marcia, Becky and Jenny,

We are deeply saddened to hear of Erik's passing. Our lives have been enriched by his friendship, and for Rob, his mentorship. And as in life, he leaves through his blog, a legacy of love, deep insight, goofiness and hope. Thank you for sharing him with the world. Much love.

—Nancy Plankey-Videla, January 23, 2019

My deepest condolences to Erik's family and friends.  
Rohini

—Rohini Hensman, January 24, 2019

My condolences. I only met Erik briefly but his work had a profound impact on my PhD thesis work and continues to inspire and inform me in current work. And as a human being. Hoping to keep working in his spirit.

—Ellinor Isgren, January 24, 2019

I am desperately sad to hear the news, and send my deepest sympathy. I am just the mother of a graduate student, and have been very impressed and grateful for Erik's care and support for all his students. His influence and inspiration will live on in those who studied with him.

—Linda Croxford, January 24, 2019

My deepest condolences to Erik's family. I was his advisee for one full decade during which he was always very supportive to me. I especially am grateful to him for his constant concern for my wife when she had a serious kidney problem. Even my son got some help from Erik when he was attending UW-Madison. He will be missed by all of us. I am glad to have had the opportunity to translate Erik's Real Utopias into Korean a few years ago. The book was well received in Korea. His legacy will live on in this distant country, too, and in my memory.

—Keedon Kwon, January 24, 2019

My deepest sympathies to Erik's immediate and extended family.

—Dana Takagi, January 24, 2019

This is so very sad to hear. I expected that Erik would be an exception to this disease just as he was an exception in all things. The exceptionally brilliant mind. The exceptionally kind professor. The exceptionally human intellectual giant. He touched so many hearts and minds and I feel lucky and privileged to have been one of them. My deepest sympathies to his family and close friends. He will be sorely missed in this world. Love.

—Sarah Kaiksow, January 24, 2019

So sorry to hear about Erik's passing. Many years ago he visited the Sociology Dept. at the University of Kansas and participated in a graduate seminar:

"The Value Controversy." This was organized by a student group known as the Marxist Collective. The Collective organized an old fashioned "hoe down"

at a barn near Lawrence. We all drank too much beer and danced well into the night. Erik played a wicked fiddle for us. He was an engaging, supportive

mentor and a new friend to all of us. I still love telling stories about his visit and the hoe down. All the best to his many friends and family.

Best, Dr. Dean Braa, Western Oregon University

—Dean Braa, January 24, 2019

I only recently learned about Erik's blog and I, too, am inspired by his writing about this last stage of life. I wrote Erik an email a day or two before he died, which he probably did not see, telling him how a little stuffed lion he gave me at a baby shower a couple of weeks before my daughter was born became a constant presence in our family. All of my daughter's friends through the years, various boyfriends, and her husband have known and loved Leo the Lion and have known that Leo was a gift of "Erik Wright, my mom's dissertation advisor." Jenny had just joined Erik and Marcia's life when I met with him before deciding to come to Madison for a PhD. He was the best supporter of grad students with babies and young children and I think this part of him -- his love of children, helped establish the importance of making children welcome at the American Sociological Association meetings and other events. We met at the West Coast Socialist Social Science conferences in the woods in Northern California (fondly called "commie camp") back when he was at Berkeley, and I'd play guitar while he played fiddle and we got people singing, and then of course he'd get people dancing. These are parts of Erik that I treasure, even more than the wonderful teacher and mentor that he was. My daughter says that 35-year-old Leo the Lion will always have a piece of Erik in him. I think Erik would like that a stuffed Lion he gave as a gift grew into a "real" lion who had tea parties, travelled to many countries, sang songs, told stories, and still sleeps in bed with his 34-year-old owner and her husband. My blessings to Marcia, Jenny, Becky, and the grandchildren, who hopefully will have a piece of their grandfather in the stories he told and gifts he gave when they are 34 years old! With love, Carolyn Howe

—Carolyn Howe, January 24, 2019

Dear Marcia, Becky, Jenny, I am so sorry about Erik's passing. He made an impact on the world in so many ways. He was my first mentor at Wisconsin, and he was just wonderful. I, like so many, many others, have learned so much from him, over the last several decades, and over the last several weeks. He was a light in the world.

—Jennie Brand, January 24, 2019

I am so sorry to hear this news. I remember Erik as such a bright light. Sending much love to all of you.

—Cathy Caro-Bruce, January 24, 2019

What a heartbreaking news. A true scholar, a caring human being. RIP. Much love to his family.

—Damon Golsorkhi, January 24, 2019

It's really sad, but I'm happy to read it was quick and that you were together supporting him and each other. A big hug from a stranger who was touched by Erik Olin Wright work.

—Diego Salazar, January 24, 2019